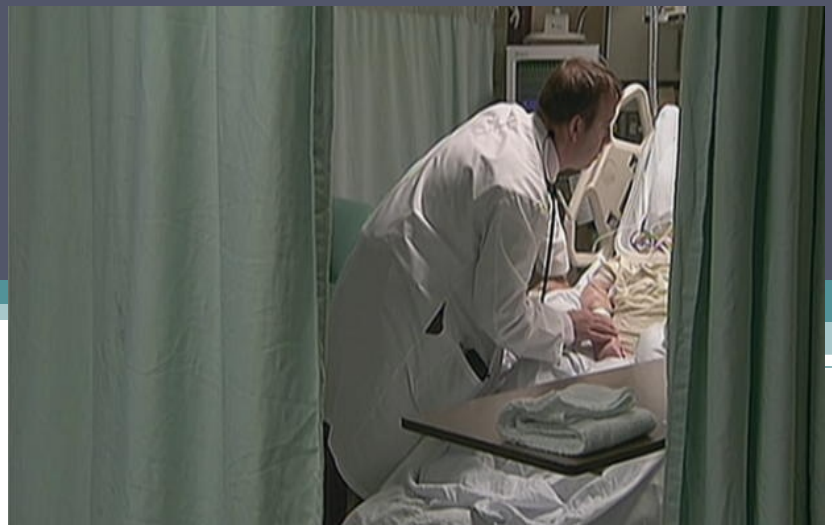
A Primer on Responding to Patient Requests for Medical Assistance in Dying (MAID)



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FACULTY/PRESENTER DISCLOSURE

- Faculty: Madeline Li
- Relationships with financial sponsors:
  - None financial

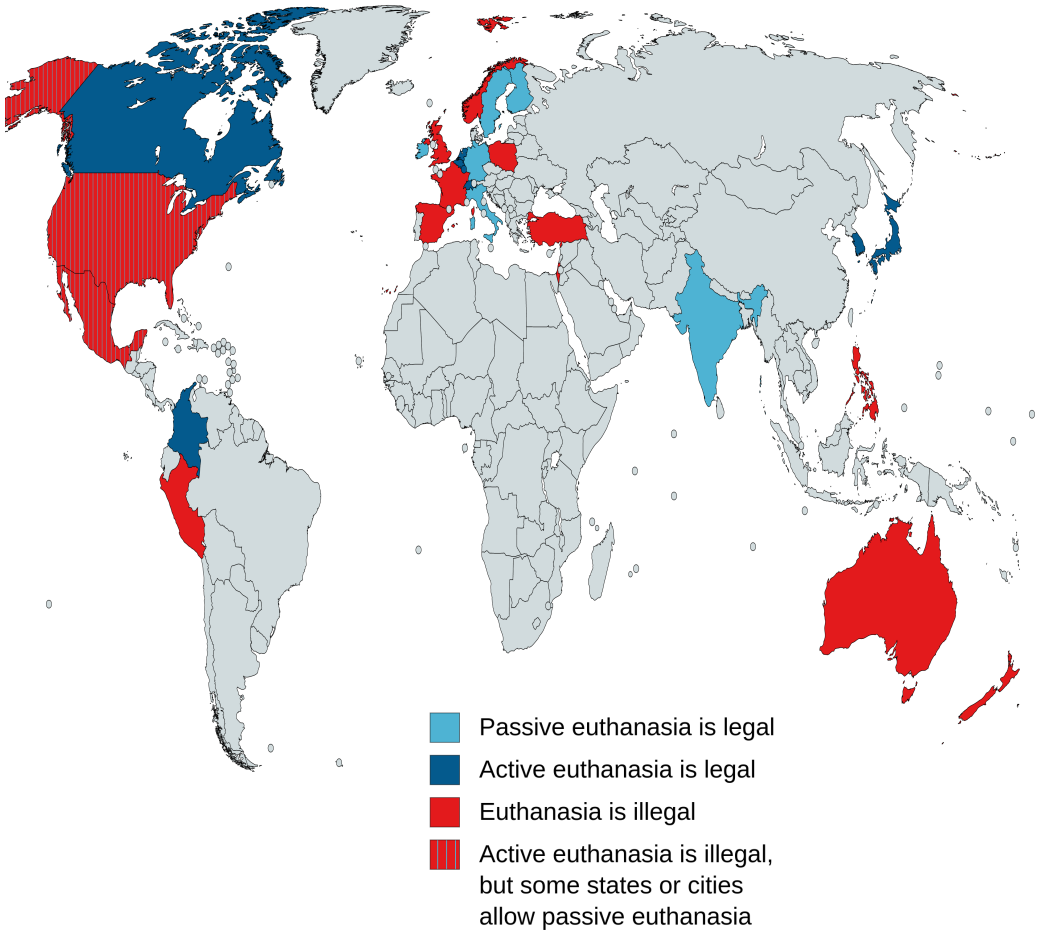
The intent of this talk is not to promote or oppose MAID

The Cultural Context

- Ageing of the population
- Increasing secularization
- Personal control and autonomy
- Consumerism and patient empowerment

The Geography of MAID

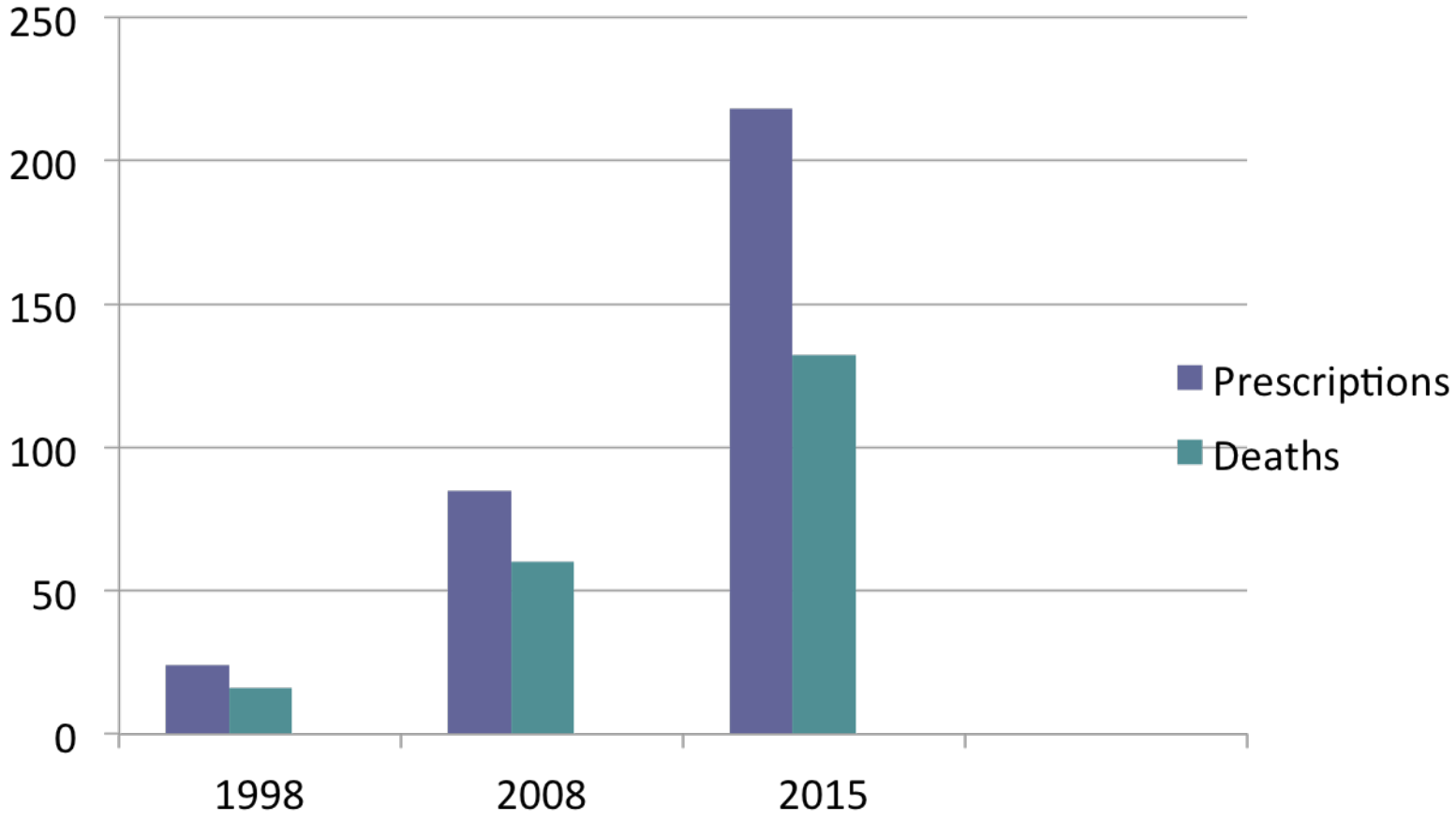
- 6 countries
  - Switzerland, Netherlands, Belgium, Luxembourg, Colombia, Canada
- 8 American states
  - Oregon, Washington, Vermont, Montana, California, Washington DC, Colorado, Hawaii
- Victoria, Australia as of mid 2019



Reasons for Requesting Assisted Dying

- Less able to participate in enjoyable activities
  - 73%
- Loss of autonomy
  - 92%
- Loss of dignity
  - 75%
- Concern about burden on family/friends/caregivers
  - 48%
- Losing control of bodily functions
  - 36%
- Inadequate pain control (or concern about this)
  - 29%
- Concern about financial consequences of treatment
  - 2.3%

Lethal Prescriptions and Deaths in Oregon



Supreme Court Ruling
Carter vs Canada (February 6, 2015)

- Prohibition on assisted dying is void (as of June 6, 2016), since it violates Section 7 of the Charter of Rights and Freedoms
  - "Everyone has the right to life, liberty and security of the person…"
  - Patients were being forced to end their lives prematurely while they were still able to do

Federal Legislation on Assisted Dying Bill C-14 (June 17, 2016)

1. Health services funded by a government in Canada
2. At least 18 years of age
3. Capable of health care decisions
4. Grievous and irremediable medical condition
5. Voluntary request for MAID
6. Informed consent after being informed of alternatives, including palliative care

- Independent review and legislative re-consideration after 2 years on
  - Mature minors
  - Advance requests
  - Mental illness as sole underlying medical condition

Grievous and Irremediable

1. Serious and incurable illness, disease or disability
2. Advanced state of irreversible decline in capability
3. Enduring physical or psychological suffering, intolerable to the patient and cannot be relieved under conditions they consider acceptable
4. Natural death has become reasonably foreseeable, …without a prognosis necessarily having been made..

Bill C-14 Safeguards

1. Patient request made in writing after being informed of grievous and irremediable illness
2. Two independent witnesses of request
3. Two independent medical practitioners confirm eligibility
4. Informed of right to withdraw request at any time, in any manner
5. At least 10 clear days between request and intervention, unless death or loss of capacity is imminent
6. Opportunity to withdraw request and express consent immediately before intervention

UHN IV MAID Protocol

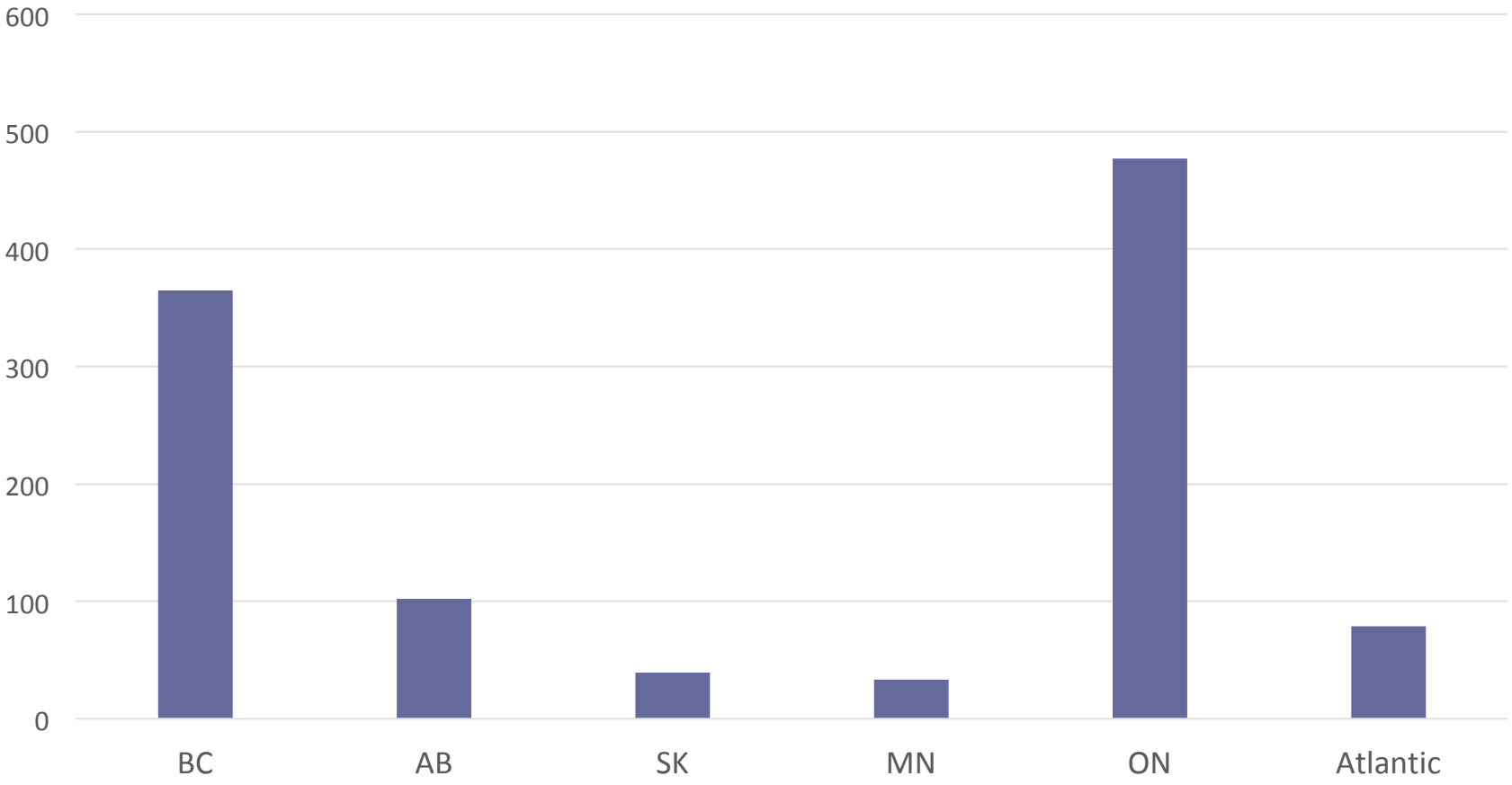
Step	Syringe Label	Drug	Indication	Rate of administration
1	Syringe A	Midazolam	For sedation	Over 10 seconds
2	Syringe B	Lidocaine	For infusion-related discomfort	Over 5 seconds
3	Syringe C	Propofol (1 of 2)	For coma induction	Over 30 seconds
4	Syringe D	Propofol (2 of 2)		Over 30 seconds
5	*confirm coma achieved*			
5b	If still responding to stimuli, administer second set of midazolam and propofol from second kit			
6	Syringe E	*Rocuronium	For muscle paralysis	Over 5 seconds

*Rocuronium should always be administered after propofol, even if respiratory or cardiac arrest has already occurred after propofol alone

Interim Federal MAID Report
(Jun 17, 2016 – Dec 31, 2017)

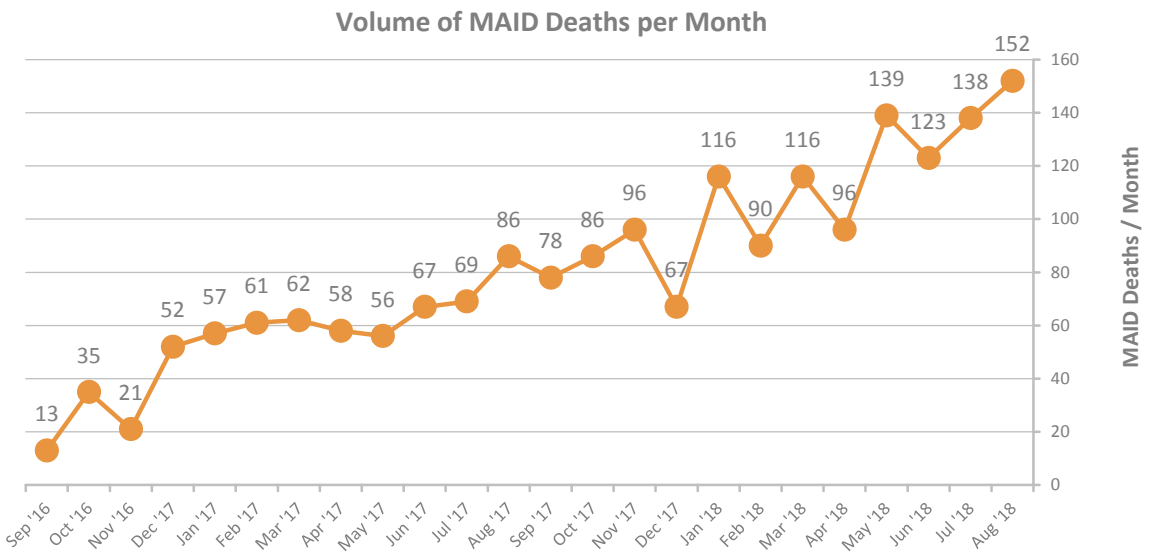
Total cases completed	**3, 714** (Excluding QC, NU, YT, NWT)
Sex	51% men; 49% women
Average age	73 years (2% under 45)
% Euthanasia	99%
Location	46% hospital, 38% home
Disease	65% - Cancer 10% - Neurodegenerative 16% - CV/Resp
Death before MAID	20%
% MAID deaths by province	BC – 1.6 QC – 0.9 Atlantic – 0.4 AB, MB – 0.8, 0.6 ON – 0.7 SK – 0.4

Numbers of MAiD Deaths by Province



VOLUMES: THE NUMBER OF MAID CASES IN ONTARIO IS GROWING

- As of August 31, 2018, there have been a total of **2000 MAID deaths in Ontario** (since June 2016).
  - 1999 clinician-administered
  - 1 self-administered
- The number of MAID deaths has grown, on average, by 19% per month.



MAID represents a notable proportion of deaths in the province of Ontario.

0.8%

In 2017, 0.8% of all deaths in the province were due to MAID.

1%

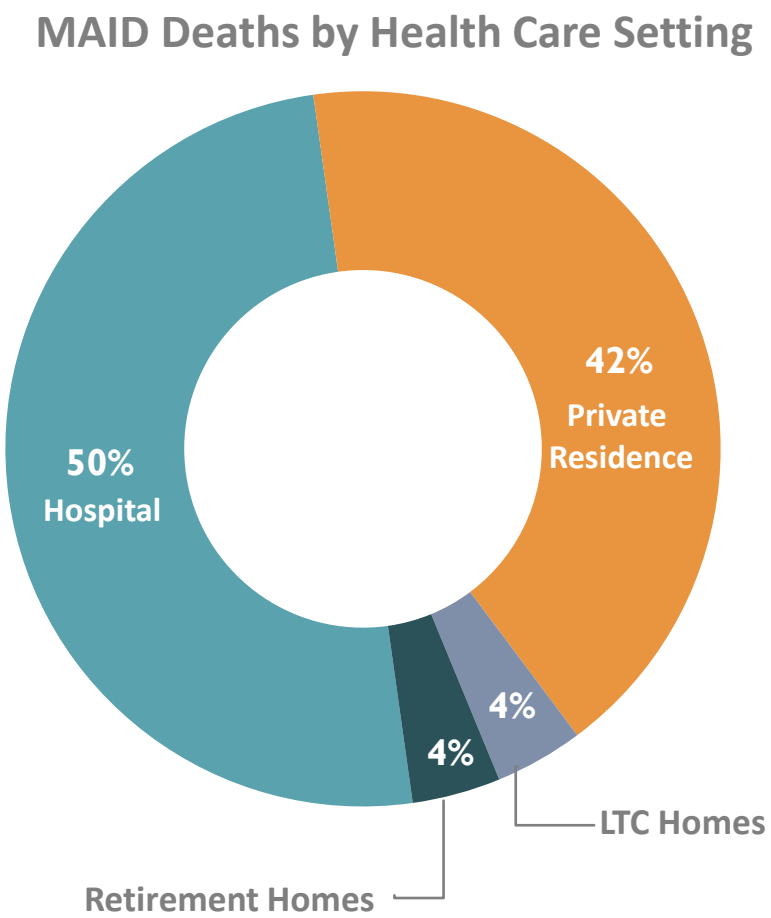
In 2018, MAID is expected to account for over 1% of all deaths in Ontario.

1.8%

In 2017, MAID accounted for 1.8% of all cancer-related deaths in Ontario.

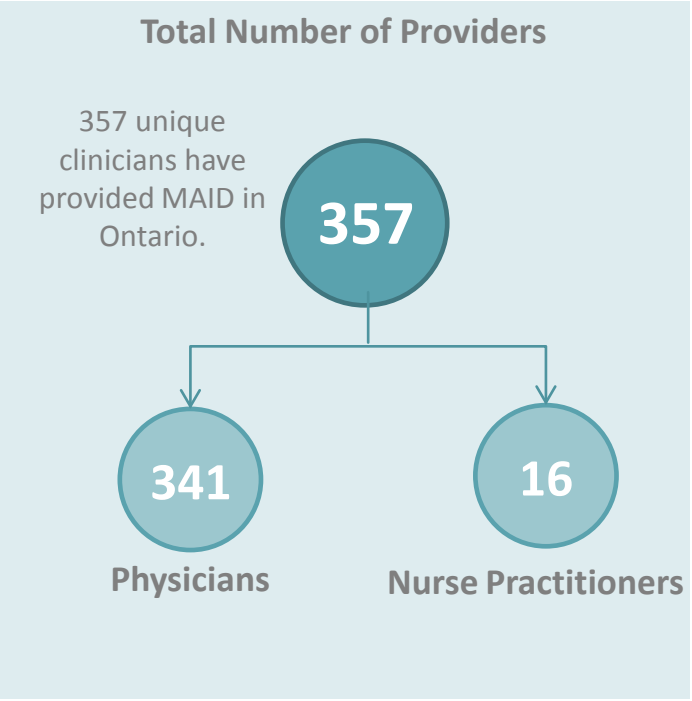
WHERE? MAID OCCURS IN A VARIETY OF SETTINGS…

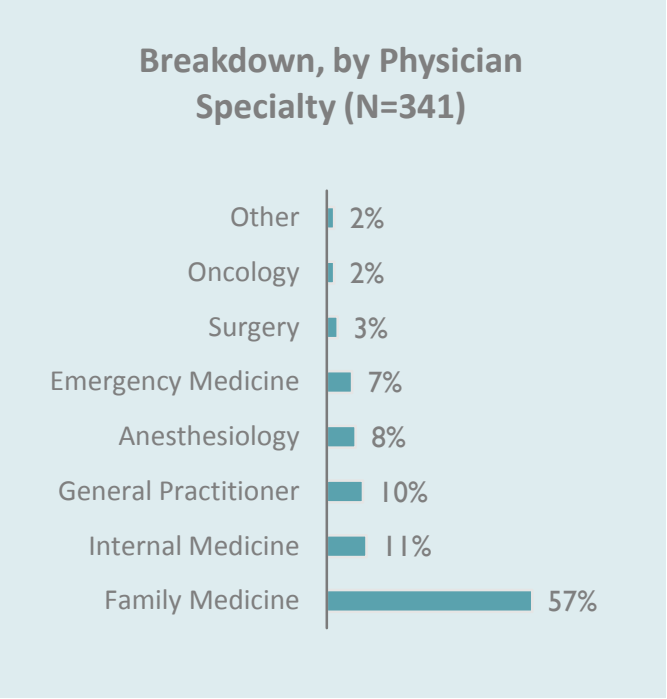
- The majority of medically assisted deaths are provided in hospital, with approximately half of MAID deaths occurring in this setting.
    - 116 hospitals have had a MAID death occur in their facility; this represents over 51% of Ontario hospitals.
- Of note, the location of the MAID death may not accurately reflect where the patient was living prior to receiving MAID.



WHO IS PROVIDING MAID?

- **The number of MAID providers has grown significantly**, from 112 unique providers in January 2017 to 357 unique providers in August 2018 – a 219% increase in a period of 19 months.
- The majority of physicians who provide MAID are **family physicians** (57%).

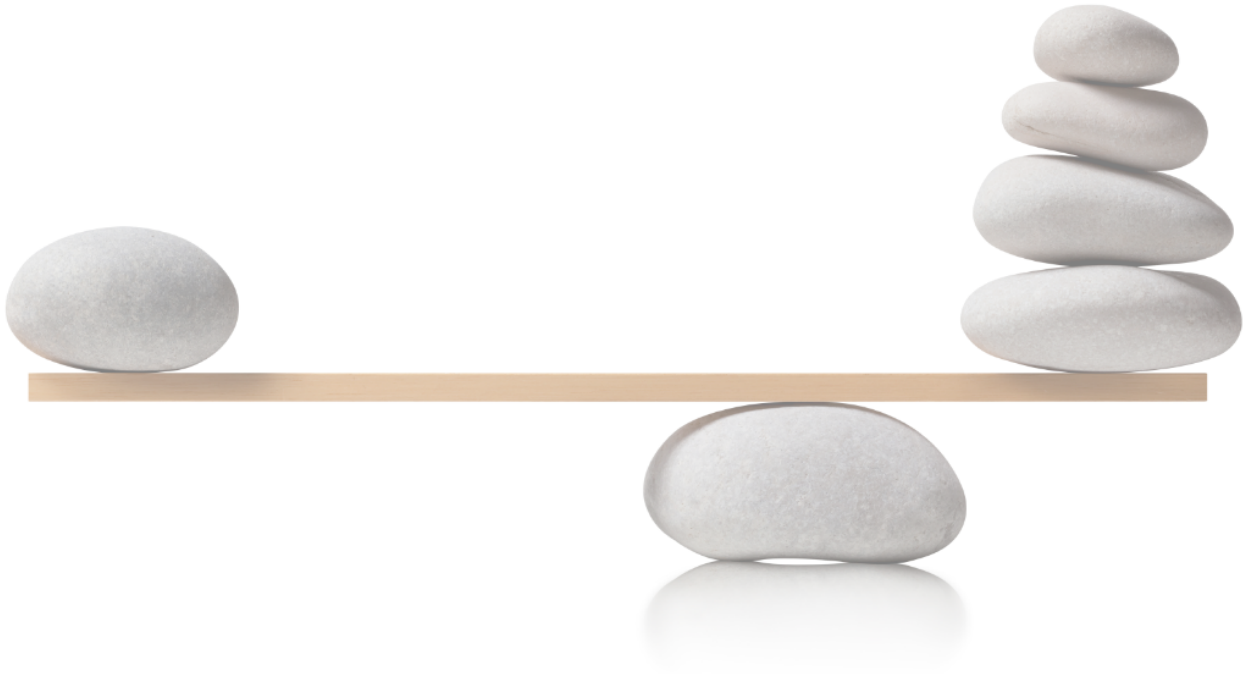




Desire for MAID

Right to access

Appropriateness



Case A

Male with NFII, recent development of brain malignancy, prognosis <6 months

- had adapted to deafness, being wheelchair bound x years, now seeking MAID due to anxiety about coping with inevitable loss of function and death
- not yet engaged in palliative care, but needed secure option of MAID as travelling for assessments, obtaining ASL translators, etc. burdensome, timing of assessment wrt loss of cognitive function
- approved based on psychological suffering − would not be able to enjoy remaining time, would sit and ruminate over timing of MAID and death process if declined
- joyfully able to complete his bucket list, did not come forward for over 9 months, urgent due to rapid deterioration
- CMPA questioned original degree of suffering, MAID re-assessments required (although no expiry dates on approvals)
- pt lost capacity, died naturally

Case B

Male cancer patient, prognosis weeks to short months

- Too weak and deconditioned for further treatment, requested MAID due to anxiety about dying/fear of suffering
- PCU bed offer withdrawn when informed of interest in MAID
- Assessed for MAID but denied because of ambivalence about receiving MAID – “80% sure I will have it”, wanting trial of steroids first to see if he could feel well enough to receive more chemotherapy
- Pt discharged home for trial of steroids, re-admitted due to failure to cope, eventually transferred to PCU
- On admission to PCU, requested MAID, pt discharged to TGH ER
- Transferred to 16p at PM, approved for MAID with enormous relief, but ambivalent about selecting a date
- Pt ultimately lost capacity before asking for MAID

Case C

Female with widely metastatic cancer including brain, prognosis of days to weeks

- history of anxiety/depression, not wanting to know prognosis or engage in end of life counseling
- wanted MAID because of existential distress - loss of vision, cognitive dysfunction, weakness with loss of independence
- mood not impacting capacity, assessed & approved for MAID with waiver of reflection period due to potential loss of capacity
- reluctant to set date, not wanting to give up days of competent life, wished an SDM could provide permission once she was no longer aware
- after an aspiration event, urgently asked for MAID, refusing pain meds to avoid confusion for intervention which was quickly arranged before weekend
- pt changed mind at last minute - following day had no memory of events
- advised MAID is not an emergency option, discussed palliative sedation is urgently available for intractable symptom crisis
- died peacefully with comfort measures

Initial MAID Conversations

SUICIDE IN CANADA

- Decriminalized in
  - 1972
- Suicide rates
  - ~1.5% of all deaths globally
  - ~3% of cancer deaths
- MAID rates globally
  - 6-10% of all deaths

What is MAID?

☑ Voluntary euthanasia

- Administration of a lethal substance to a person by a medical practitioner or nurse practitioner at their request

☑ Assisted dying

- prescribing a substance to a person, at their request, for them to self-administer and cause their own death

X Suicide

- Ending one's own life without medical assistance (ie. without medical eligibility assessment and safeguards)

Can I raise the option of MAID?

- Bill C14 241(1): Everyone is guilty of an indictable offence if they counsel or aid a person to die by suicide
  - *MAID ≠ suicide*
- Bill C14 241(3): No person is a party to an offence if they do anything for the purpose of aiding a medical practitioner or nurse practitioner to provide a person with medical assistance in dying
- It is legal and appropriate to raise the option of MAID if appropriate in the context of goals of care discussions
  - "Are you aware assisted dying is an option in Canada now?"
  - "Is assisted dying something you would ever want to talk about or consider?"
  - ***"Informing, not recommending"***

Conscientious Objection

- *Carter v Canada* made MAiD a patient right, but also indicated the need to reconcile this with physician's rights to refuse participation
- Bill C-14 neither compels physicians to provide MAiD, **nor to refer**

Rights

- RCPSC Professional Obligations and Human Rights Policy, "Physicians do not have to provide services that conflict with their conscience or religious beliefs"
- MOHLTC: "No clinicians **or institutions** would be required to participate directly in MAiD cases"

Limitations

- CPSO policy requires conscientiously objecting physicians to make an "effective referral" to a non-objecting physician
- Must not abandon non-MAiD related usual care, or else entirely transfer care

Initial MAID Conversations

1. **Desire to die statements are first an opportunity for discussion about symptoms and goals of care**
   - Not an automatic referral for MAID

2. **Important MAID process points:**
   - Home or hospital location – not easily switched
   - Need for 2 witnesses and who they can be
   - Required 10 day reflection period to ensure sustained intent

3. **Advise patients on timing of MAID application**
   - Need to apply when certain of intent to receive MAID *instead* of alternatives (although can change their minds)
   - Not so late to lose capacity
   - Not so early they need to be re-assessed

Initial MAID Conversations

5. **Advise patient that all MAID deaths are Coroner cases**
   - autopsies are rare, but advance identification of funeral home and next of kin to speak to the coroner

6. **Paradoxical requests for MAID based on anxiety about death**
   - often urgent requests in actively dying patients, not optimal for patient's quality of death, or MAID resources
   - ask patient to imagine moment of holding arm out for lethal injection

7. **Detailed discussion of nature of palliative care and palliative sedation**
   - means and limitations of symptom control, what a natural death might look like
   - palliative sedation simpler to arrange, possibly less anxiety provoking, available urgently, not lingering for weeks

MAiD & Palliative Sedation

MAID	Palliative Sedation
Incurable illness, prognosis 1 year (reasonably foreseeable death)	Terminal illness, prognosis hours to days (up to 2 weeks)
Subjective physical or psychological suffering, unrelievable by any means acceptable to the patient	(Objective) intractable symptom (eg dyspnea, pain, N&V, anxiety), refractory to all alternatives
Capacity and consent by patient	Consent by pt or SDM
2 assessors required	Consult 2nd PC physician, unless emergency
Psychiatric consultation not required	Psychiatric consult required, unless emergency
Goal is death − permanent	Goal is consciousness reduction - short-term, intermittent or continuous
Burdensome process and documentation forms	Document verbal consent and process in chart as routine clinical care
Religious objections	Accepted by faith based organizations
Immediate death	Days to short weeks to death
Not available urgently	Available urgently for symptom crisis
Attention to support for family and staff	Attention to support for family and staff

Top 8 MAiD FAQs

1. What is the typical timeline for MAiD?
   - On average, 2 weeks from signing the Patient Request Form, including assessment times and the required 10-day reflection period
   - May be longer for patients deemed to require a longer reflection period
   - May be shorter if death or loss of capacity is imminent
2. Can an SDM/POA request MAiD for a patient?
   - No, the request must be from a capable patient, without coercion
3. Can health care providers witness MAiD requests?
   - No, witnesses cannot provide health care services or personal care to the patient
   - Witnesses also cannot be beneficiaries, which excludes most family members
   - Most often witnesses are friends
4. Who can sign a MAiD request on behalf of a patient unable to sign?
   - Anyone who is not a beneficiary, including health care providers

Top 8 MAiD FAQs

5. Do patients need to wait and see if other treatments help?
   - No, patients do not need to try any options they find unacceptable
   - Even incurable is defined as "***incurable by any means acceptable to the patient***"

6. Can people with mental illness access MAiD?
   - No, mental illness cannot be the sole underlying medical condition
   - However, having a mental illness concurrent with a grievous and irremediable medical condition does not necessarily make a patient ineligible if they are capable

7. Is MAiD only for terminal illness?
   - Spirit of the law suggests terminal illness, but people with chronic health conditions can meet the letter of the law by refusing treatment

8. What can I tell patients about how MAiD will affect life insurance policies?
   - In Ontario, the underlying illness is listed as the cause of death, with no mention of MAID or suicide
   - MAiD is not considered to be suicide in legislation, the Coroner will work with families to ensure that MAiD does not affect a patient's life insurance

NEW Federal MAID Reporting Requirements

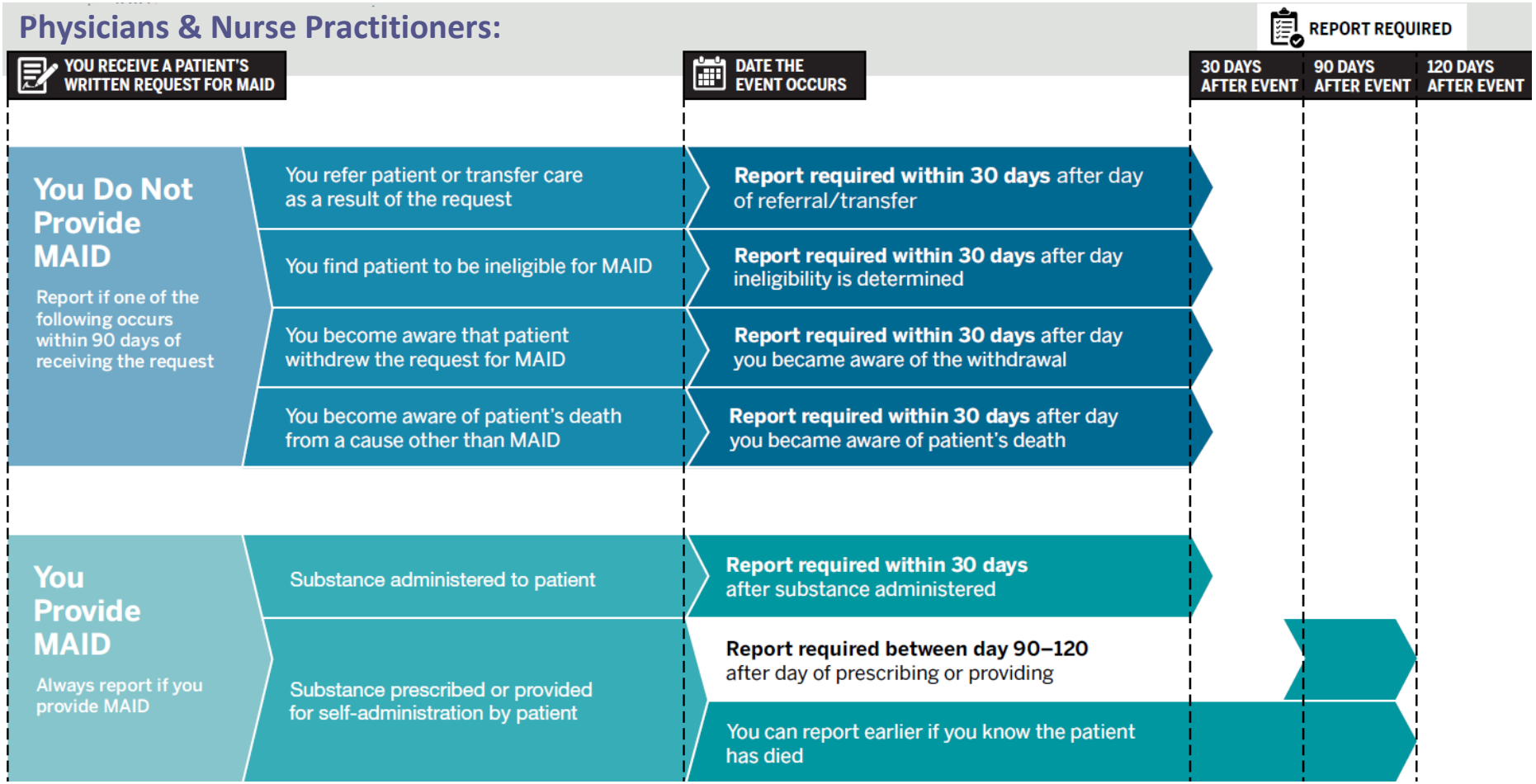
- *Criminal Code* requires reporting of MAID activities for the purpose of monitoring
  - http://gazette.gc.ca/rp-pr/p2/2018/2018-08-08/html/sor-dors166-eng.html
  - ➢ Failure to report could result in maximum prison term of 2 years, although a 5 level oversight process will occur first

- A patient making a **written request** for MAID assessment triggers the requirement to report
  - Not equivalent to the formal safeguard requiring witnesses (Clinican Aid A in Ontario)
  - More than an inquiry or request for information, a serious request for MAID assessment
  - Can take any form including a text or e-mail

- Reporting required whether patient receives MAID or not, and even when you refer a patient elsewhere for MAID

- Reporting process varies by province, but comes into effect on November 1, 2018
  - https://www.canada.ca/en/health-canada/services/medical-assistance-dying/reporting-requirements.html for more information and to access reporting portal
  - **Email:** hc.maid.report-rapport.amm.sc@canada.ca **Phone:** 1-833-219-5528

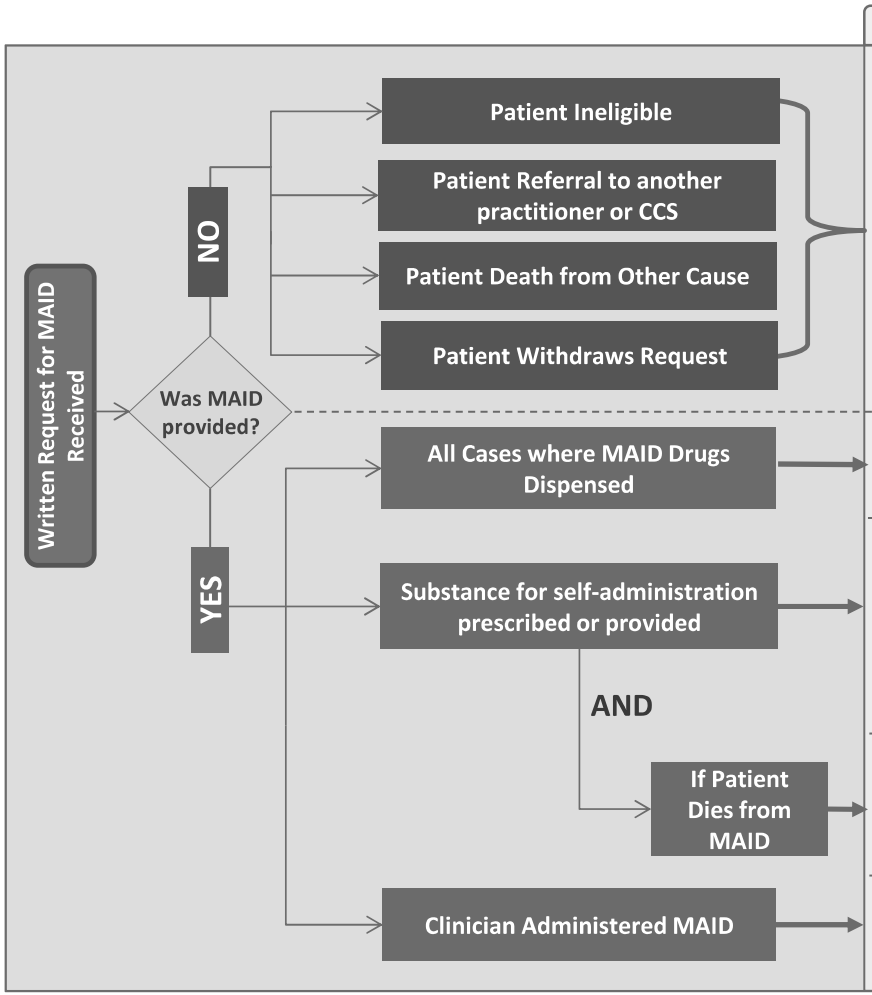
Timelines for reporting



Pharmacists: Must always report within 30 days after the day on which the substance was dispensed.

Hybrid Designated Recipient Role: Ontario's Proposed Approach (cont'd)

- Under federal legislation, MAID may be provided in two ways: by **administering a substance to the patient (clinician administered)**, or by **prescribing or providing a substance to the patient for the purpose of self-administration**. In the latter scenario, provision of MAID may not result in the death of the patient, or there may be a significant time lag between provision and death, depending on the patient's actions. This will influence the reporting requirements.



REPORT TO	WHO	WHEN	WHAT
Health Canada via Stats Canada Portal	Physician/NP who receives request	Within **30** days of the outcome (not receipt of the request)	Schedule 1,4
			Schedule 1, 2
			Schedule 1 (+ Schedule 3 & 4, if pt. found eligible prior to dying from another cause)
			Schedule 1 (+ Schedule 3 & 4, if patient found eligible prior to withdrawing request)
Health Canada via Stats Canada Portal	Dispensing Pharmacist	Within **30** days of dispensing the drugs	Schedule 8
Health Canada via Stats Canada Portal	Prescribing Physician/NP	No earlier than **90 days** and no later than **120** days (unless practitioner becomes aware of death from any cause in <90 days)	Schedule 1, 3, 4, 5, 6
Office of the Chief Coroner	Prescribing Physician/NP	**Immediately** after physician/ NP becomes aware of MAID death	**Status Quo Reporting** (includes info from Schedule 1, 3, 4, 5, 6)
Office of the Chief Coroner	Administering Physician/NP	**Immediately** after death is confirmed	**Status Quo Reporting** (includes info from Schedule 1, 3, 4, 5, 7)

Who Receives MAID?

- Misconception that patients who request MAID experience unbearable pain or psychosocial vulnerability
- Those who request MAID either have death anxiety or don't
- Those with significant death anxiety tend not to complete MAID, but the option of MAID is powerfully therapeutic to them
- Those who receive MAID tend to be:
  - Successful
  - Affluent
  - Educated
  - High life satisfaction
  - Prioritize control
  - Often not psychologically minded
  - Not afraid of dying

MAID Resources

- Training:
  - CMA courses: https://www.cma.ca/En/Pages/education-eol-care-medical-assistance-dying.aspx
  - Centre for Effective Practice guide: https://thewellhealth.ca/maid/
- MOHLTC:
  - Clinician Referral Service, referral for initial assessment or second opinion, toll-free: **1-844-243-5880**
  - Clinician Aid A (Patient request); Clinician Aid B (Primary Clinician); Clinician Aid C (Secondary Clinician): http://www.health.gov.on.ca/en/pro/programs/maid/default.aspx
  - Patient information pamphlet: http://www.health.gov.on.ca/en/pro/programs/maid/docs/maid.pdf
- Information:
  - CAMAP - Canadian Association of MAID Assessors and Providers: http://camapcanada.ca/
  - UHN MAID website and e-learning module: http://www.uhn.ca/healthcareprofessionals/MAID