

Medical assistance in dying through the lens of dementia

Jocelyn Downie

11th Canadian Conference on Dementia

November 4, 2023

Conflicts of interest

- No conflicts to disclose
 - No financial support for research
 - No relationship with sponsors of conference

MAiD through the lens of dementia

- **Can** people with dementia legally get MAiD?
- **Are** people with dementia getting MAiD?
- **Are** advance requests for MAiD permitted under the law?
- **Should** advance requests for MAiD be permitted under the law?
- **Will** advance requests for MAiD be permitted under the law in the future?

Can people with dementia
get MAiD?

YES

Eligibility criteria

- Eligible for health services funded by government in Canada (or would be but for minimum period of residence or waiting period) ✓
- At least 18 years old ✓
- Capable of making decisions with respect to their health ✓
- Made a voluntary request ✓
- Gave informed consent to receive medical assistance in dying after having been informed of means available to relieve suffering, including palliative care ✓

Eligibility criteria

- Have a grievous and irremediable medical condition
 - they have a serious and **incurable** illness, disease or disability; and
 - they are in an advanced state of irreversible **decline in capability**; and
 - that illness, disease or disability or that state of decline causes them enduring **physical or psychological suffering** that is intolerable to them and that cannot be relieved under conditions that they consider acceptable

Serious and incurable ✓

Advanced state of irreversible decline in capability

- irreversible ✓
- “advanced state” ✓
 - relative to **person** (can be advanced long before loss of decision-making capacity)
 - **proximity to** loss of decision-making capacity can itself = advanced
- “capability” ✓
 - physical and/or **cognitive** decline

Enduring, intolerable, irremediable suffering*

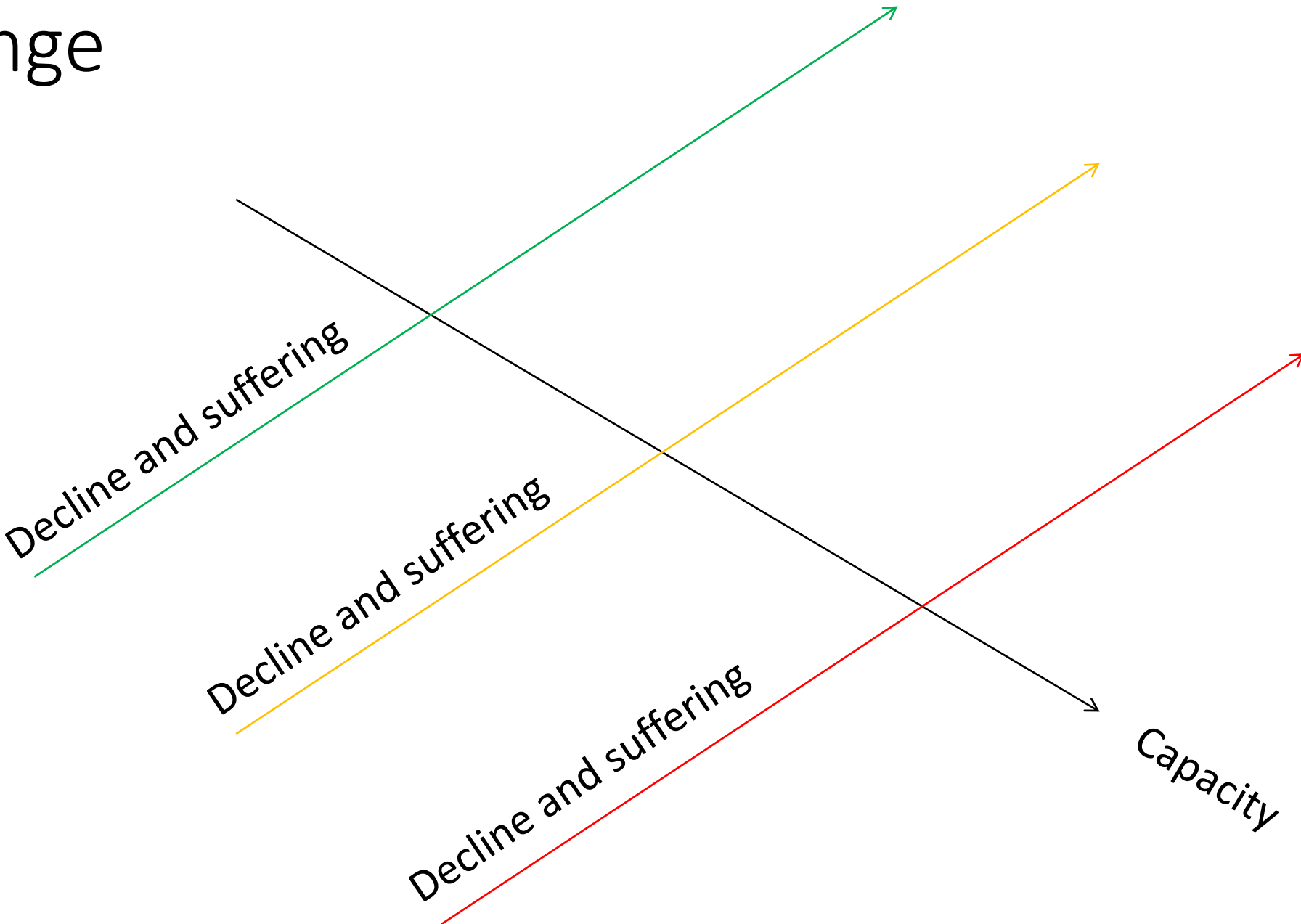
- enduring ✓
- intolerable ✓
- irremediable ✓

*subjective

Procedural safeguard

- immediately before providing the medical assistance in dying, give the person an **opportunity to withdraw** their request and ensure that the person gives **express consent** to receive medical assistance in dying.

Challenge



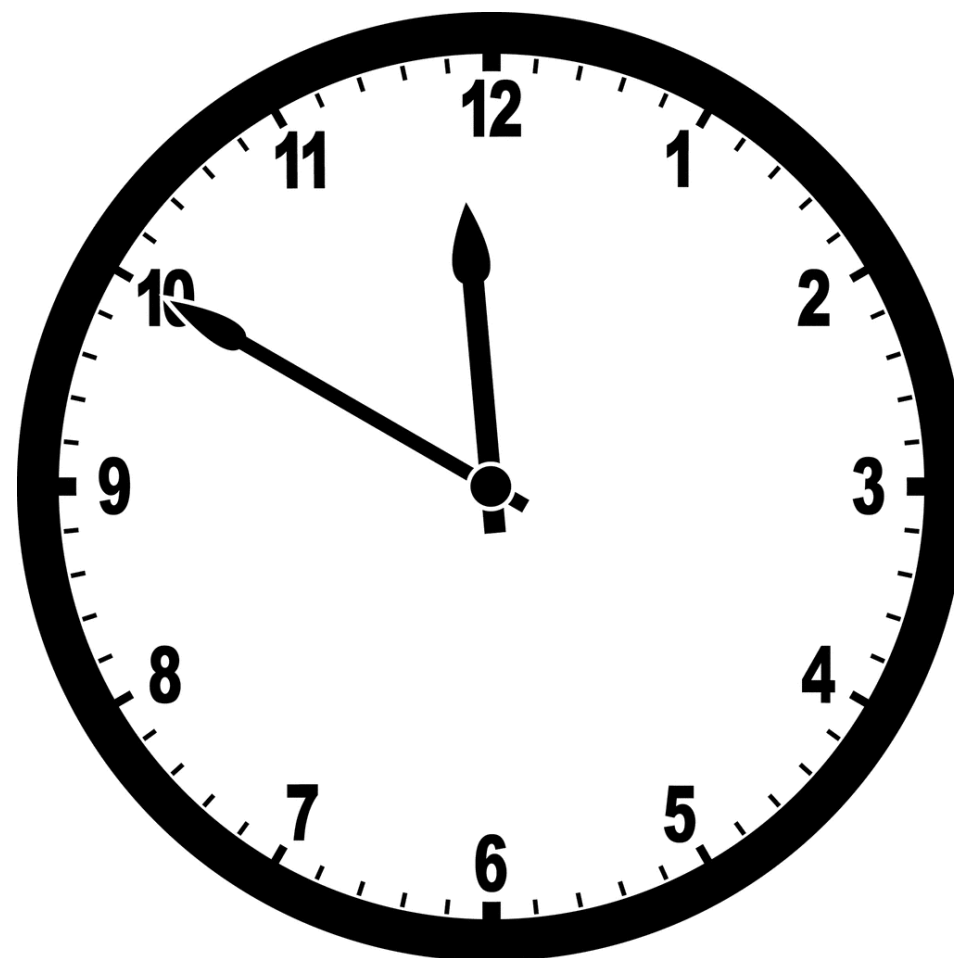
Current solutions

Ten minutes to midnight

+/-

Final consent waiver

“Ten minutes to midnight”



camapcanada.ca

Final consent waiver

- Natural death has become reasonably foreseeable
- Meets all eligibility criteria for MAiD
- At risk of losing capacity to consent to MAiD
- “Written arrangement” between patient and provider
 - agree to provision of MAiD on or before a specified date if lose capacity prior to that date
- Person doesn't demonstrate resistance or refusal*

*involuntary words, sounds, gestures made in response to contact do not = refusal or resistance

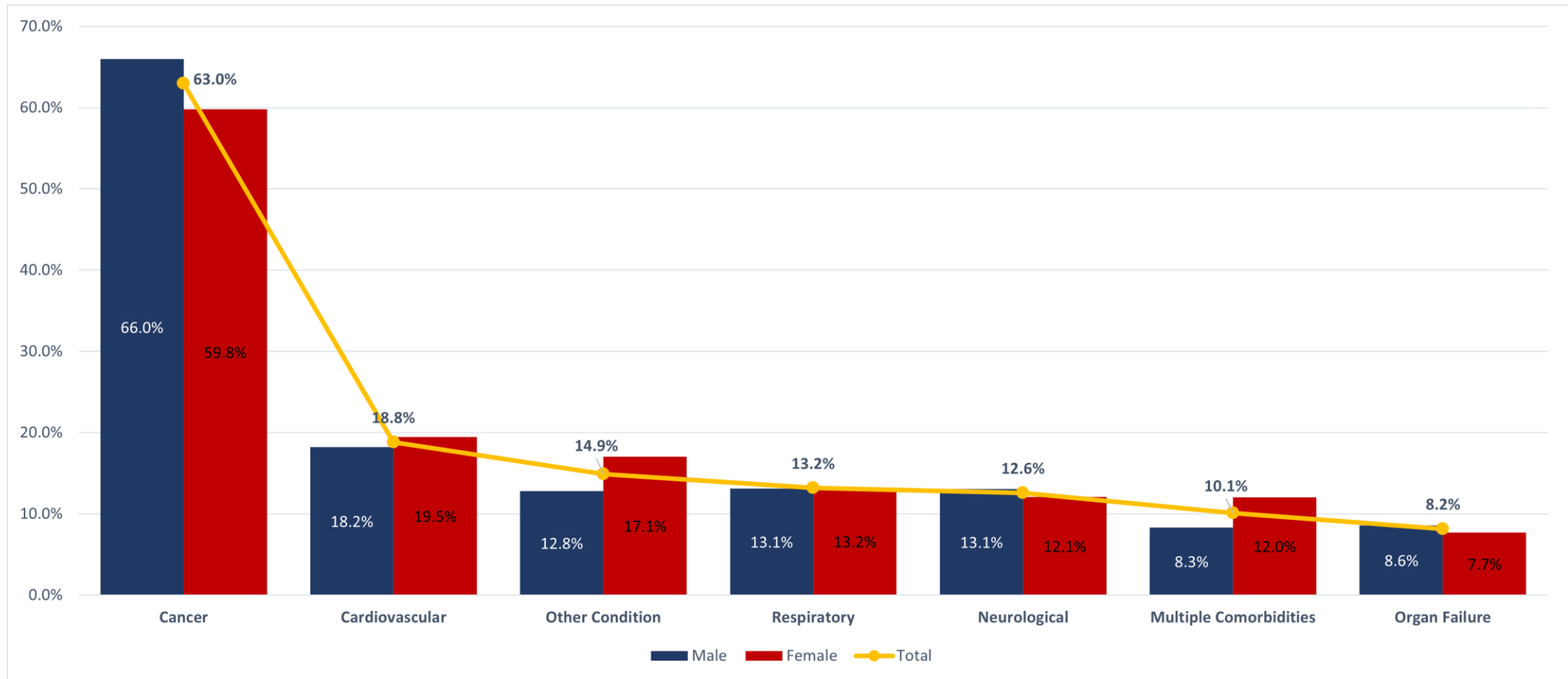
Consequences

- Dying sooner than would like to ensure can get MAiD
- Hit midnight so no MAiD
- No clinicians available to do “ten minutes to midnight” protocol +/- final consent waiver so no MAiD

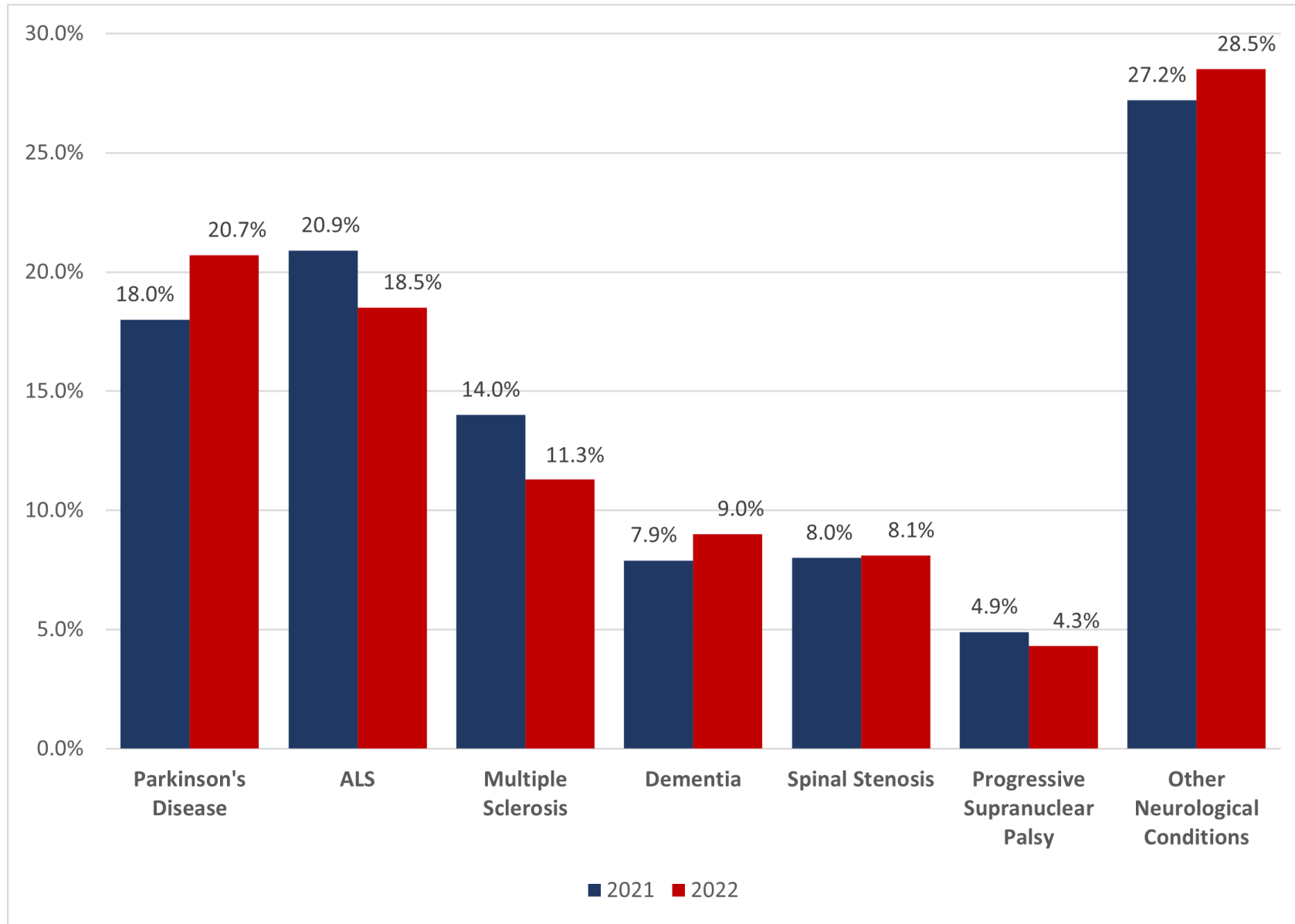
Are people with dementia
getting MAiD?

YES

Underlying conditions in MAiD deaths 2022



“Neurological”



Barriers to accessing MAiD for persons with dementia?

- All MAiD
 - More requests than clinicians can meet
 - Institutional religious objection
- Specific to dementia
 - Challenge of intersection point (capacity and suffering/decline in capability)
 - Lack of understanding of eligibility criteria
 - think persons with dementia are captured by mental disorders exclusion clause
 - don't know about "ten minutes to midnight" and final consent waivers

One possible solution

Advance requests for MAiD

Are advance requests for MAiD
permitted under the law?

MOSTLY NO

Final consent waiver and other advance requests

Final consent waiver

- **After** all eligibility criteria have been met

Other advance requests

- **Before** all eligibility criteria have been met

- After diagnosis with serious and incurable condition

OR

- Anytime

Current law

- Must be able to give consent immediately prior to the provision of MAiD **unless...**
- have final consent waiver **but...**
- that's only available **after** all eligibility criteria met

Consequences

- Huge public pressure to amend the law to allow requests for MAiD to be made **before** the eligibility criteria have been met
 - Some argue for before **all** of the eligibility criteria have been met (e.g., after diagnosis with serious and incurable condition but before the others)
 - Some argue for before **any** of the eligibility criteria have been met

Should advance requests for MAiD be permitted under the law in the future?

DEPENDS ON WHO YOU ASK

Main features of the policy debate re: MAiD for people with dementia

Benefits

- Autonomy
- Suffering
- Consistency with withholding and withdrawal
- Comfort knowing it will be available
- Alternative is cruel (starvation and dehydration)
- Longer life

Concerns

- How know when suffering conditions met
- Disability paradox
- Different understandings of concepts of autonomy, identity, personhood
- Indifferent, expresses desire to live, actively resists MAiD
- Appearance of absence of suffering
- Moral distress care providers

Major MAiD reports with recommendations re: dementia

- Royal Society of Canada 2011 ✓
- Provincial/Territorial Expert Advisory Group 2015 ✓
- Special Joint Committee House and Senate 2016 ✓
- Special Joint Committee House and Senate 2023 ✓

Civil society

- Alzheimer Society ✓
- Parkinson Canada ✓
- Dying with Dignity Canada ✓
- Council of Canadians with Disabilities X*
- Inclusion Canada X *

* Opposed to allowing substitute decision-makers (but that's not what is being considered)

Alzheimer Society

“The Alzheimer Society of Canada supports the right of people living with dementia to make an advance request for a medically assisted death.

The Alzheimer Society recognizes that people living with dementia are individuals – first and foremost. They have the same rights as everyone else, including the right to participate in decisions about their life and care. We respect the rights of all people with dementia to advocate for their individual best interests, including advocating for access to MAID through advance requests.”

Public opinion

- 82% support advance requests for those with a grievous and irremediable condition
- 72% support advance requests even if no grievous or irremediable medical condition

Will advance requests for MAiD
be permitted under the law in
the future?

YES & MAYBE

YES – Quebec

by June 2025 (predicted in 2024)

- When create advance request
 - be capable of giving consent to care
 - suffer from serious and incurable illness leading to incapacity to give consent to care
- At time of administration of MAiD
 - be incapable of giving consent to care due to illness
 - still meet eligibility criteria
 - be exhibiting, on a recurring basis, **the clinical manifestations related to their illness that they described in the request**
 - ...

YES – Quebec

by June 2025 (predicted in 2024)

- be in a medical state:
 - of advanced irreversible decline in capability; and
 - that gives competent professional cause to believe, **based on the information at their disposal and according to their clinical judgment**, that the patient is experiencing enduring and unbearable physical or psychological suffering that cannot be relieved under conditions considered tolerable.
- ...

MAYBE - Canada

- Senator Wallin Bill S-248
 - declaration made after a diagnosis of a serious and incurable illness, disease or disability, but no more than five years have elapsed since the declaration was made
 - person has lost capacity
 - person is suffering conditions related to their serious and incurable illness, disease or disability that are identified clearly in the declaration and can be observed by the medical practitioner or nurse practitioner
- *passed second reading in Senate in June 2023 – waiting on Senate Standing Committee on Legal and Constitutional Affairs*

MAYBE Canada

- Advocacy to amend *Criminal Code* to allow advance requests where:
 - Capable at time of drafting
 - After diagnosis with serious and incurable illness, diseases, or disability
 - Clearly articulated and observable indicators of intolerable suffering

Come back for the 12th
Canadian Conference on
Dementia

to see whether “maybe” turns into “yes” or “no”

eol.law.dal.ca

jocelyn.downie@dal.ca