ALS SLA
CANADA

ALS Society of Canada
Société de la SLA du Canada

Medical Assistance in Dying

A Canadian Perspective

International Symposium on ALS/MND
Tammy Moore, CEO, ALS Society of Canada
Perth | December 2019

Challenging the law

Gerry Hahrmann, Province

Challenging the law

“If I cannot give consent to my own death,
whose body is this? Who owns my life?”
Sue Rodriguez, diagnosed with ALS August 1991

- under section 241(b) of **Canada’s Criminal Code**, anyone who "...aids or abets a person to commit suicide, whether suicide ensues or not, is guilty of an indictable offence and liable to imprisonment for a term not exceeding fourteen years”
- **Canadian Charter of Rights and Freedoms, Sections 7, 12, 15**
- Supreme Court decision against her on September 30, 1993
- February 12, 1994, with the assistance of an anonymous doctor, she took her own life

Challenging the law

Darryl Dick, Canadian Press

ALS.CA

Challenging the law

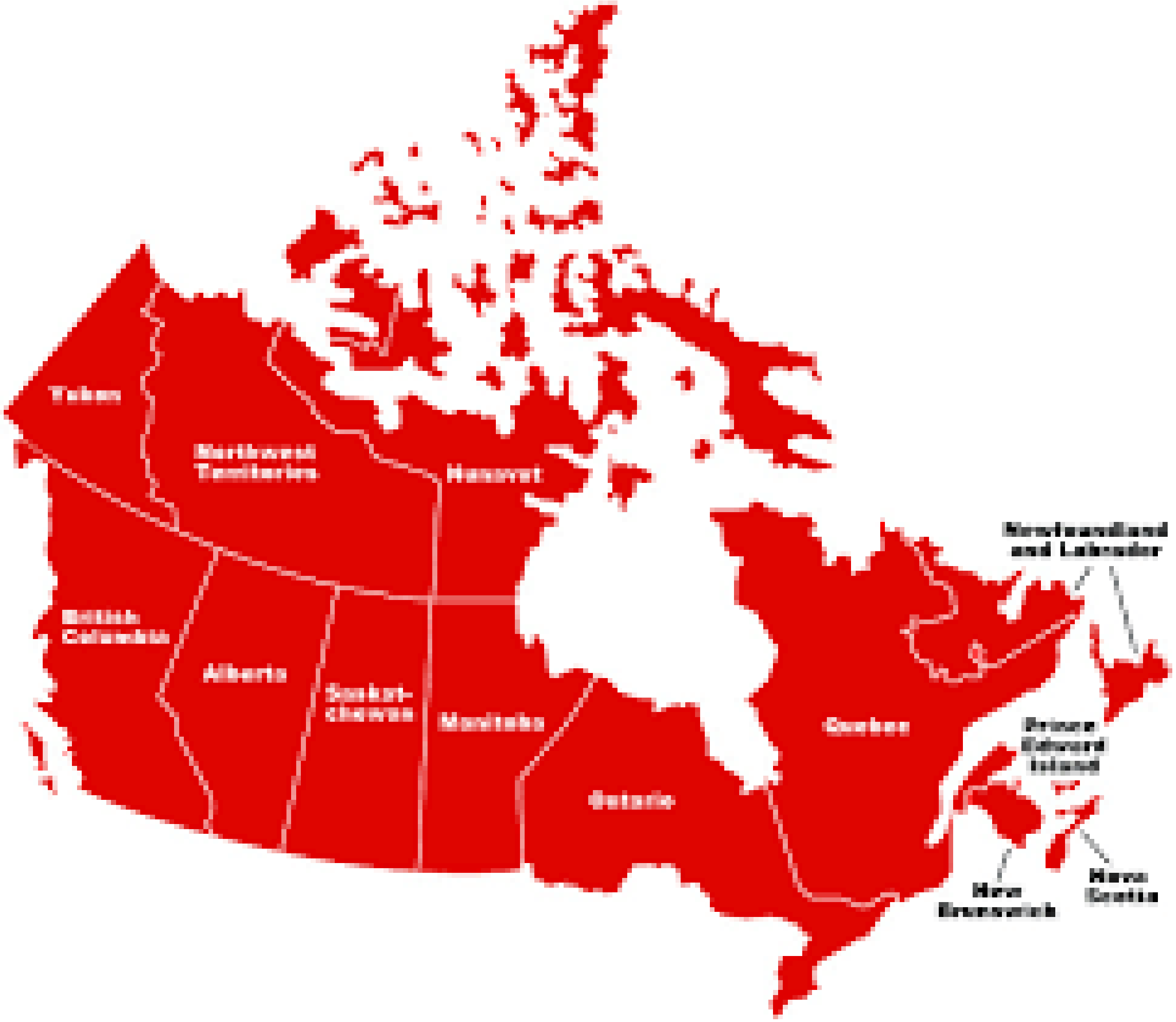
Gloria Taylor, diagnosed with ALS 2009

- Challenged **Canadian Charter of Rights of Freedoms**
- Argument that prohibition of assisted dying:
  - Sec 15: **discriminates** against people with degenerative diseases who have no physical means to end their lives without assistance,
  - and, Sec 12: **right to life** because, if they do want to end their suffering, they would have to do so earlier than they might otherwise want, before they lose the capacity to act.
- In **2012, B.C. Supreme Court ruled that the right to die with dignity is protected by the Charter of Rights and Freedoms**

Federal Legislation

- **June 7, 2016, physician-assisted suicide became legal in Canada**
- The **Supreme Court** unanimously struck down parts of section 241(b) and section 14 of the Criminal Code which the justices ruled unjustifiably infringed on section 7 of the Charter of Rights and Freedoms
- **Federal Parliament** passed Bill C-14 which laid out the rules that allow doctors and nurse practitioners to legally end the lives of terminally ill who are suffering and whose deaths are 'reasonably foreseeable’

Federal Legislation
Provincial Implementation



Federal Legislation

- The federal practice may not be consistent with a health care provider's beliefs and values.
  - The federal legislation does not force any person to provide or help to provide medical assistance in dying.
- Provincial and territorial governments have the responsibility for determining how and where health care services are provided.
  - They may make policies around where medical assistance in dying can take place as long as they do not conflict with the Criminal Code.

Eligibility Criteria

To receive medical assistance in dying, a patient must:

- be eligible for publicly funded health care services in Canada,
- be 18 years of age or older,
- be capable of making health care decisions,
- have a grievous and irremediable medical condition:
  - has a serious and incurable illness, disease or disability,
  - is in an advanced state of irreversible decline in capability,
  - is enduring physical or psychological suffering, caused by the medical condition or the state of decline, that is intolerable to the person,
  - natural death has become reasonably foreseeable

Process

- **Voluntary request** made writing, signed and dated by, or on behalf of, the person after they are informed of diagnosis
- **Two independent witnesses** must sign and date the request
- **Eligibility criteria sign off** by initial medical/nurse practitioner
- **Second opinion** signed by a medical/nurse practitioner
- At least **10 clear days between request and MAiD** — or if the loss of capacity to provide informed consent, is imminent
- At any time and in any manner, **request may be withdrawn**
- Immediately before providing MAiD, the person is given an **opportunity to withdraw their request**, or confirm their intent

Organization approach

- Concerns with advocating for or against MAiD during legislative challenges and writing of legislation
- Took a neutral position, focused on need to have appropriate palliative resources in place to support people to have a choice to live with ALS
- Monitored process for challenges for people with ALS in access, and would have advocated if necessary
  - Written consent, spoken consent
  - Death within 6 months vs is reasonably foreseeable
- Ambiguity of who could offer information/counsel and be protected by legislation

Three years later

- More than 6,749 medically assisted deaths between June 2016 – October 2018
- Majority 56 and 90 years of age
- Average age 72
- Larger urban centres (56%) compared to areas with smaller populations (44%)
- Primarily in a hospital (44%) or in a patient’s home (42%)
- Cancer-related (62%), circulatory/respiratory system (15%), neurodegenerative (14%), and other causes/unknown (9%)
- Not tracked to level of ALS

Health Canada, Fourth Interim Report on Medical Assistance in Dying, April 2019

ALS Canada | Support Services

- ALS Canada Regional Managers support pALS and cALS in the community to navigate their journey with ALS
  - Emotional support
  - Provide information
  - Identify community resources
  - Interact with healthcare resources
- MAiD specific support requests
  - Discussions about end of life, request for information
  - Independent witness
  - Attendance during MAiD

Issues

- Without appropriate supports and palliative options people with ALS may feel they have no other choice
- Emotional toll on healthcare practitioners and staff
- Not all healthcare practitioners or institutions support MAiD which can create challenges with access, especially in smaller or more rural locations
- Emerging legal challenges around mental capacity, youth, foreseeable death – need to balance with protecting vulnerable people

Observations

- Empowerment
- Ability to celebrate life lived
- ‘Good death’ experience
- Live longer
- Organ donation
- Tissue donation for research

Tammy Moore, CEO
ALS Society of Canada
tmoore@als.ca
416.803.9237

Overview

In June 2016, legislation for Medical Assistance in Dying (MAiD) was brought into law in Canada after several patients, including Gloria Taylor, who was living with ALS, challenged the Supreme Court for the right to die.

Tammy Moore, CEO of the ALS Society of Canada will share the learnings gained during the period of debate and formulation of the legislation and the realities three years after the implementation of the law. The presentation will include the role of the individual, the community and the ALS Society in challenging and influencing the right and ability to access Medical Assistance in Dying.

Three years after the law was passed, what is the impact on the ALS community in Canada, the reality of access and follow-through. The presentation will explore the position the ALS Society has taken and the need to support staff as they support the ALS community.

As ALS Canada looks to the future with MAiD, what are the unintended outcomes including organ donation and advocacy initiatives.