Background Supporting Documentation: Position Statement on Medical Assistance in Dying (MAID)

Contents

Preamble

On July 13, 2016, the Parkinson Canada Board of Directors passed a motion approving the development of a Parkinson Canada position statement on Medical Assistance in Dying (MAID). The motion was requested by the Government Relations and Advocacy Committee after a review of the issue was conducted following the criteria specified in the Parkinson Canada Process for Preparing Position Statements, which is a Board approved process (May 14, 2016 – Board meeting).

History of the Issue

On Feb. 6, 2015, the Supreme Court of Canada, in a unanimous decision, struck down the federal prohibition on physician-assisted dying (PAD), arguing the old law violates the *Canadian Charter of Rights and Freedoms*.

The Supreme Court gave the government until June 6, 2016 to prepare for the decriminalization of assisted dying.

On June 17, 2016, Bill C-14 received Royal Assent. The objectives of the legislation include:

- recognizing the autonomy of persons who have a grievous and irremediable medical condition that causes them enduring and intolerable suffering to seek medical assistance in dying;
- recognizing that robust safeguards, which reflect the irrevocable nature of ending a life, are essential to prevent error and abuse in the provision of medical assistance in dying;
- affirming the inherent and equal value of every person's life and avoiding encouraging negative perceptions of the quality of life of persons who are elderly, ill or disabled;
- protecting vulnerable persons from being induced, in moments of weakness, to end their lives;
- recognizing that suicide is a significant public health issue that can have lasting and harmful effects on individuals, families and communities;
- recognizing that permitting access to medical assistance in dying for competent adults whose deaths are reasonably foreseeable strikes the most appropriate balance between the autonomy of persons who seek medical assistance in dying, on one hand, and the interests of vulnerable persons in need of protection and those of society, on the other;
- recognizing that a consistent approach to medical assistance in dying across Canada is desirable, while recognizing the provinces' jurisdiction over various matters related to medical assistance

in dying, including the delivery of health care services and the regulation of health care professionals, as well as insurance contracts, coroners and medical examiners;

- recognizing that those who wish to access medical assistance in dying should be able to do so without adverse legal consequences on their families;

- recognizing that everyone has freedom of conscience and religion under section 2 of the *Canadian Charter of Rights and Freedoms* and that nothing in the Bill affects those freedoms (as amended by the House of Commons Standing Committee on Justice and Human Rights);

- recognizing the Government of Canada's commitment to working with provinces, territories and civil society to facilitate access to palliative and end-of-life care, care and services for individuals living with Alzheimer's and dementia, appropriate mental health supports and services and culturally and spiritually appropriate end-of-life care for Indigenous patients (as amended by the House of Commons Standing Committee on Justice and Human Rights).

Current Status

Bill C-14 enacts a new section of the *Criminal Code*, which in essence sets out the criminal rules surrounding the provision of medical assistance in dying. New subsections set out the eligibility criteria for such assistance in Canada.

Under the new federal legislation, MAIDis available to a person who meets all of the following criteria:

- being an adult (at least 18 years old) who is mentally competent ("capable") to make health care decisions for themselves;

- having a grievous and irremediable medical condition;

- making a voluntary request for medical assistance in dying which does not result from external pressure;

- giving informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care; and,

- being eligible for health services funded by a government.

A grievous and irremediable medical condition is expressly defined under the Bill as:

- having a serious and incurable illness, disease or disability; and,

- being in an advanced state of irreversible decline in capability; and
- experiencing enduring physical or psychological suffering, due to the illness, disease, disability or state of decline, that is intolerable to the person and cannot be relieved in a manner that they consider acceptable; and,

- where the person’s natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without requiring a specific prognosis as to the length of time the person has left to live.

The federal government has committed to “uphold the principles set out in the *Canada Health Act* and to develop non-legislative measures to support the improvement of a full range of options for end-of-life care and respect the personal convictions of health care providers”. In this regard, the Minister of Health will develop, in collaboration with the provinces and territories, an end-of-life care coordination system to provide information on options and facilitate patient access to care.

The federal government has also committed to explore additional circumstances, in which a person may seek access to MAID, namely requests by mature minors, advance requests, and where mental illness is the sole underlying medical condition. These circumstances are complex, and require additional study and consideration. The Bill requires the Minister of Justice and the Minister of Health to initiate one or more independent reviews on these three issues no later than 180 days after Bill C-14 receives royal assent (amendment from the House of Commons Standing Committee on Justice and Human Rights) and must report back to Parliament no later than 2 years after the reviews are initiated (amendment from the Senate).

Position Statement and Rationale

Parkinson Canada’s position on medical assistance in dying (MAID) is guided by the Supreme Court of Canada’s decision, current Canadian federal legislation, and evidence-based research that include extensive community consultation.

Parkinson Canada’s position touches on four critical points of MAID:

1. The need for accessible and optimal palliative care that is responsive to pain and depression
2. Canada’s legislation regarding reasonably foreseeable death
3. Canada’s legislation regarding advanced care directives
4. Parkinson Canada’s role with the public

Palliative Care

Parkinson Canada also strongly recommends that the Government of Canada invest in accessible and optimal palliative care for people with advanced neurodegenerative diseases, which includes the best screening and management of pain and depression.

Canadians with Parkinson’s also deserve an equal opportunity to access treatment and care in the advanced stages of the disease. As documented in the Canadian Parkinson Guidelines (2012), there are challenges to accessing palliative care with Parkinson’s disease. The two factors that contribute most to these concerns are the long duration of Parkinson’s and the difficulty in predicting the time of death In addition it is concerning that depression is a common non-motor symptom of Parkinson’s disease, with as many as 50 per cent of people with Parkinson’s experiencing the symptoms of clinical depression during the course of the disease. Canadians with Parkinson's should not be left to make decisions about end-of-life care out of fear or despair.

Reasonably Foreseeable Natural Death

Parkinson Canada calls on the Government of Canada to follow the Supreme Court's direction that specifies that MAID should be available where "grievous and irremediable" medical conditions are present that are causing enduring suffering that the person finds intolerable*, and requests that the additional criteria regarding reasonably foreseeable natural death be removed.

The current Canadian legislation stipulates that a person is eligible for MAID if they have (among other criteria) a "grievous and irremediable medical condition" which does not need to be "fatal or terminal"; however "natural death" is "reasonably foreseeable". Parkinson Canada is concerned about the ambiguity regarding this crucial criterion. Parkinson's disease is not considered a fatal disease and the progression of the disease can vary depending on other contributing factors (i.e. age, overall health). A determination of "reasonably foreseeable natural death" may be difficult to ascertain in many people with Parkinson's disease, while at the same time having met all other criteria to be eligible for MAID. Canadians with Parkinson's deserve clarity about the options that are available to them so they, along with their loved ones, can plan for the future.

Advanced Consent

Parkinson Canada supports the use of advanced consent for medical assistance in dying when suffering becomes intolerable later in the disease course whether or not the person has competency Parkinson Canada looks forward to the Government of Canada's independent review to study advance consent and MAID that was set to commence within 180 days of the date Bill C-14 received Royal Assent (June 17, 2016).

Dementia occurs in approximately 30 per cent of people with Parkinson's and usually occurs in the late stages of the disease, which makes the issue of advance directives a particular concern for the Parkinson's community. The current legislation restricts the access of MAID to competent adults, and does not allow for advance directives. Parkinson Canada, in accordance with the Canadian Guidelines on Parkinson's disease, believes that people with Parkinson's and the person designated as decision-maker should initiate discussions about end-of-life and advanced care planning early in the disease process.

The legislation stipulates that the federal government will conduct further studies to examine the legal, medical and ethical questions around situations, including advanced consent. The results of these studies will help to inform future reviews of the legislation.

Parkinson Canada's Roles and Responsibilities

Parkinson Canada encourages anyone looking for more information about MAID to speak to their health care provider about individual options, as well as the specific provincial/territorial professional guidelines that govern the practice of MAID for their area.

The rationale for the Parkinson Canada role is based on the direction from the federal government from both the Bill and the government's discussion documents. Key federal government statements include:

For greater certainty, the Bill clarifies that no social worker, psychologist, psychiatrist, therapist, medical practitioner, nurse practitioner or other health care professional commits an offence if they provide information to a person on the lawful provision of medical assistance in dying (provision added by the House of Commons Standing Committee on Justice and Human Rights).

Patients are encouraged to contact their physicians or nurse practitioners (if applicable) for questions about access. Some provinces and territories may have developed other information and coordination resources, and these will be posted as available.

Physicians and nurse practitioners are encouraged to contact their provincial or territorial regulatory body for information about guidelines.

The Canadian Nurses Protective Society (CNPS) is a national, not-for-profit society to provide appropriate professional liability protection to their members, and to protect the public they serve. The CNPS offers the following to nurses:

The provision of objective information is not prohibited by the Criminal Code nor is it impacted by the changes brought about by Bill C-14. Further, Bill C-14 incorporates a clarification that permits NPs and other health care professionals to provide information about the lawful provision of MAID to a patient (section 241 (5.1)). RNs can share information and engage in discussions about MAID with their patients.

However, RNs must be mindful that subsection 241(a) of the Criminal Code will continue to make it a criminal offence to "counsel" a person to commit suicide. For the purposes of the Criminal Code, "counsel" means encourage, solicit or incite. Due to the criminal significance of the word "counsel," an RN must be mindful not to encourage or incite a patient to seek MAID.

To reduce the risk of allegations of counselling, within the meaning of the Criminal Code, it would be prudent for nurses not to participate in the preparation of any written request for MAID made by the patient, such as the completion of a standardized MAID request form used within their employer institution.

RNs may also chose to refer a patient's inquiries about MAID to their treating physician or NP, to a designated MAID health care team, if available, or to health institution personnel who may be in a better position to respond to questions about services available at the institution.

Given the government direction and the additional precautions being recommended to the nursing profession, it is prudent for Parkinson Canada staff and representatives not engage in any discussion with the public about MAID other than to refer people to their physician or health care provider should they express an interest in this option.

It is also important to note that guidelines are established in the provinces and territories; therefore it is critically important for individuals to understand from their health care provider what the additional guidelines are that govern their practice.

Moving forward

All Parkinson Canada staff will be informed of this position statement MAID, and trained on the organization's role and responsibility with the public on this topic.

For additional information on the federal legislation on MAID, please visit: http://www.healthycanadians.gc.ca/health-system-systeme-sante/services/end-life-care-soins-fin-vie/medical-assistance-dying-aide-medicale-mourir-eng.php#a3

Consultation and Research

Parkinson Canada's position statement is guided by the Supreme Court of Canada's decision, Canada's federal legislation and extensive consultation and research.

Community Survey

- 244 Canadians impacted by Parkinson's disease responding to the following question: *"As someone who is connected to the Parkinson's community, what are your thoughts on Physician Assisted Dying as an end of life option and what considerations should be made?"* 77% were in clearly in favour, 23% were clearly not in favour.

Parkinson Canada's Medical Advisory Committee (MAC)

- The MAC consists of xx health and allied health professionals.
- MAC members provided their professional knowledge and experience. Key feedback from the MAC included:
    - The need for a focus on palliative care
    - Additional issues impacting patients (i.e. caregiver burden, home and community care services, long term care waitlists);
    - Suggestions to ensure clarity of the statement;
    - Examples from their respective practices.

Positions/Input from other organizations

- Dying with Dignity: Lead of Dying with Dignity expressed that Parkinson Canada has a role to play, not in commenting on whether or not assisted dying is right or wrong, but on the point that Parkinson's should not be a condition that excludes people from certain end of life options. Excerpt from the Dying with Dignity website: *Despite assurances from the federal government that individuals do not have to be terminal in order to qualify, medical practitioners will ultimately have to interpret the eligibility criteria for themselves. There is a strong chance that many providers will interpret the "reasonably foreseeable" clause to mean that only those individuals whose deaths are imminent will qualify for MAID. In fact, some Canadian doctors have already been advised by lawyers to err on the side of caution and to only provide MAID to those who are terminally ill.*
  This means individuals who were granted the right to a peaceful death by the Supreme Court may now found themselves barred from access. For example, patients with excruciating conditions like ALS, Multiple Sclerosis, and Parkinson's disease are at risk of being denied a dignified death because

their deaths may not be imminent. Other individuals, like those who have endured a serious stroke or a series of strokes, may also be trapped in intolerable suffering with no natural end in sight. For many of these individuals, this intolerable suffering can persist for years, and to force them to continue languishing in agony is exactly the kind of fate the Supreme Court ruled against.

- Alzheimer Society of Canada (ASC) position: ASC believes that because we cannot predict future suffering, providing advance consent for MAID should not be possible for people with dementia. ASC believes that people with dementia need to be safeguarded as they will be extremely vulnerable at the end of their life. People with dementia do not have the capacity to make an informed decision and consent to end their life at the later stages of the disease.

- MS Society response: In a letter address to the Prime Minister, they state the following –The requirement that death must be "reasonably foreseeable" in order to qualify for medical assistance in dying lacks clarity. This requirement may prevent those who face grievous, intolerable and irremediable suffering but whose death is not imminent from exercising their constitutional right. Calling on the Government of Canada to seek clarification from the Supreme Court of Canada in a reference to determine whether or not the requirement at 241.2 (2) (d) of Bill C-14 that a patient's death within a period of time is not too remote is consistent with Carter v. Canada.

- Huntington Society response: Do not promote or dismiss assisted dying, but do provide information so families can make informed decisions that meet their needs. It is an individual choice.

Other key contacts

- Rob Oliphant, MP, Co-Chair of the **Special Joint Committee on Physician-Assisted Dying.** Argues that the "reasonably foreseeable" clause added only a lack of clarity. The criteria including "be at a point where your natural death has become reasonably foreseeable which takes into account all of your medical circumstances" and "You do not need to have a fatal or terminal condition." creates an issue of who determines the seemingly contradictory statements and who adjudicates it if there is a difference of opinion? Rob also confirmed that calling for "natural death is reasonably foreseeable" to be removed from the legislation would help provide clarity for patients and physicians. He provided the following article that discusses the unreliability of predicting death: http://www.theglobeandmail.com/life/health-and-fitness/health-advisor/can-doctors-actually-predict-how-long-patients-have-left/article30500639/

- Dr. Keith Wilson, Associate Professor, Brain and Mind Research Institute, University of Ottawa. Dr. Wilson developed interview-based methods for assessing the palliative care population, which have been used to address such problems as loss of dignity, burden to others, suffering, acceptance, and the desire for death. His work has served to inform the ongoing debate in Canada about euthanasia and physician-assisted suicide. Discussion with Dr. Wilson raised the following points:

- There is broad public support for providing access to assisted dying interventions in scenarios involving terminally ill patients in unremitting physical pain. There is substantially less endorsement for scenarios that involve psychological, social, or existential sources of distress.

- Considerations need to be given to the treatment of depression and pain for people expressing a desire to die. Dr. Wilson's research explored the key different between desire for death to escape despair, fear of future suffering, and the readiness to let go.

- The Canadian Nurses Protective Society
    - Their information on the role of nurses guides our rationale for Parkinson Canada's role with patients and families.

- Other Parkinson Staff were consulted (i.e. Clients Services and Communications)

*Please note that Parkinson Canada has been influenced by many other sources outside of those named specifically in this document. We are connected with a broad network of other organizations, including the Canadian Medical Association, Neurological Health Charities Canada, Health Charities Coalition and many others.

Many of our tireless volunteers have provided input at the committee and Board tables. They bring their personal and professional experience, as well as their passion for improving the lives of all Canadians living with Parkinson's.

Of upmost importance for us are those with Parkinson's. Parkinson Canada walks the journey with people with Parkinson's and our work is forever shaped by their needs. The communities' needs are captured from our many touchpoints with the community (i.e. support groups, client services, community events, and surveys though our extensive community volunteer program ("Ambassador Network").