Position Paper: Physician-Assisted Dying

Canadian Civil Liberties Association

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Canadian Civil Liberties Association (CCLA)

The Canadian Civil Liberties Association (CCLA) is a national, non-profit, non-partisan and non-governmental organization supported by thousands of individuals and organizations from all walks of life. CCLA was constituted to promote respect for and observance of fundamental human rights and civil liberties and to defend and foster the recognition of those rights and liberties.

CCLA's major objectives include the promotion and legal protection of individual freedom and dignity. For the past 51 years, CCLA has worked to advance these goals, regularly appearing before legislative bodies and all levels of court. CCLA intervened in the case of *Carter v. Canada (Attorney General)*¹ and argued that the absolute prohibition on assisted suicide was a violation of section 7 of the *Canadian Charter of Rights and Freedoms* that could not be upheld. The Supreme Court's decision now requires both federal and provincial legislatures to address the issue of physician-assisted death, and CCLA is grateful to have the opportunity to share its position and perspectives, at this time, regarding the development of new legislative regimes on this issue, through this paper.

Overview

The legalization and regulation of assisted dying is new to Canada, and presents several complex challenges. There are many issues to be addressed, some of which require medical or clinical knowledge that is outside the scope of CCLA's expertise. CCLA will however, seek in this position paper to (i) identify some general guiding principles that should inform both the federal and provincial/territorial approaches to assisted dying, (ii) discuss the respective roles of the provincial/territorial and federal governments, and (iii) outline safeguards and criteria that will assist in striking an appropriate balance between personal autonomy and the protection of particularly vulnerable individuals.

Core Principles

CCLA's submissions on the question of the appropriate legislative scheme to respond to the Supreme Court decision in *Carter v. Canada* are informed by a number of core principles, articulated below. These principles are foundational prerequisites for any scheme that regulates assisted dying.

1. Charter Protected Right

The Supreme Court in the *Carter* case held that the prohibition on physician-assisted dying violates the section 7 *Charter* rights of competent adults who are suffering intolerably as a result of a grievous and irremediable medical condition. The Court concluded that the violation of the right to life, liberty and security of the person was severe and could not be justified. In

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¹ 2015 SCC 5 ["Carter"].

recognizing that the prohibition was, in some cases, forcing individuals to end their lives earlier than they would have liked, the Court found a violation of the right to life. The decision also notes that a concern for individual autonomy and dignity underlie the protection of the right to liberty and security of the person. The Court states:

An individual's response to a grievous and irremediable medical condition is a matter critical to their dignity and autonomy. The law allows people in this situation to request palliative sedation, refuse artificial nutrition and hydration, or request the removal of life-sustaining medical equipment, but denies them the right to request a physician's assistance in dying. This interferes with their ability to make decisions concerning their bodily integrity and medical care and thus trenches on liberty. And, by leaving people like Ms. Taylor to endure intolerable suffering, it impinges on their security of the person.²

Significantly, the Court's decision was not a question of allowing individuals to choose death over life. Instead, it allows suffering individuals some measure of control over how and when their lives will end. In crafting a legislative and regulatory framework for assistance in dying, it is important to recall that Canadians have had a limited right to choose how and when to end their lives for some time. Attempted suicide has not been a criminal offence since 1972, and refusal and withdrawal of life-saving treatment are long-standing options for those faced with the circumstances that require them to make these choices. However, the criminal law has been an obstacle for some individuals who are suffering immensely and feel ready to end their lives, but cannot do so safely and effectively without assistance.

Accordingly, as a matter of the constitutionally protected right to life, liberty and security of the person, and on the basis of the vital importance of personal autonomy and the dignity of all human beings, CCLA welcomes a change that will allow suffering individuals to make a decision about the end of their lives, and provide them with lawful means to obtain assistance in ending their lives with dignity, if that is their choice.

CCLA also takes the position that death in these circumstances should be treated, for all intents and purposes, as death from the individual's underlying medical condition.³

2. Grievous and Irremediable Condition

The Supreme Court's decision dealt with the rights of individuals who are suffering intolerably from a grievous and irremediable condition. The Court noted that such a condition may be the

² *Ibid.*, para. 66.

³ For greater clarity, the role of physician assistance would be acknowledged in terms of reporting and monitoring the practice of physician-assisted death and on a death certificate. However, to the extent any insurance consequences might flow from characterizing a death as a "suicide", the CCLA's position is that these consequences should not result where the individual has obtained physician-assistance in compliance with the existing legislative and/or regulatory regimes.

result of an illness, disease or disability and that the relevant perspective is whether the suffering is intolerable to the individual in the circumstances of his or her condition. In addition, the Court held that "irremediable" does not require a person to undertake treatments that are unacceptable to them.⁴

There have been some suggestions that an individual must be suffering from a condition that is "terminal" in order to take advantage of assisted-dying. Indeed, the recently-passed Québec legislation requires that individuals be at the "end of life" in order to access the physician-assisted dying option. CCLA does not agree that a "terminal illness" is a prerequisite to accessing physician-assisted death, particularly because that term may be considered unduly vague. Further, pursuant to the Court's decision in *Carter*, this requirement would violate the section 7 rights of individuals who are suffering greatly but whose death is not imminent.⁵

The components laid out by the Supreme Court in *Carter* establish the minimum requirements for a new legal regime. Indeed, the Court specified that the scope of its declaration was "intended to respond to the factual circumstances in this case" and that the court was not pronouncing on other situations where physician-assisted dying may be sought. As such, provincial governments may choose to go beyond these minimum requirements and make assistance in dying available to a larger demographic. While CCLA is not opposed to this possibility, we also note concerns about equal access across the country, and the benefits that would accrue from avoiding a patchwork of federal and provincial schemes and requirements nation-wide, as described further below.

3. Equality of Access

The Supreme Court's decision in *Carter*, as described above, recognized that denying the option of a physician-assisted death to competent adults who are suffering as a result of a grievous and irremediable condition violates section 7 of the *Charter*. The Court in *Carter* did not have to consider whether the prohibition on assisted dying violated s. 15 of the *Charter*, the equality guarantee. A scheme that functions inequitably, and denies access to physician-assisted death to

⁴ Carter, supra note 1, para 127.

⁵ See Jocelyn Downie and Simone Bern, "Rodriguez Redux" (2008) 16 Health L.J. 27 at 49. Downie and Bern provide a draft federal statute to amend the Criminal Code and create an exception for physician-assisted dying. They include the following note: "There is no reference in the statute to "terminal illness" as a prerequisite for requesting assistance. The term is too vague and would leave the statute open to a Charter challenge. There is no precise science to providing a prognosis of a terminal illness in terms of a specific length of time. Health care providers cannot be accurate enough, and if the statute does not include a time restriction then the condition "terminal illness" becomes too broad....the term is potentially overinclusive if used as a sufficient (but not necessary) condition to request assistance in death...Alternatively, if the term "terminal illness" is made a necessary condition in the statute, then it would be underinclusive: there are many individuals whose lives are no longer worth living to them who have not been diagnosed with a terminal illness. They may be suffering greatly and permanently, but are not imminently dying. There is no principled basis for excluding them from assisted suicide."

⁶ Carter, supra note 1, para. 127.

such individuals in the circumstances described by the Court, will remain unconstitutional on the basis of section 7^7 and could also be found to violate section 15. The equality concern could be raised again if a scheme is developed that restricts the options of some individuals based on irrelevant personal characteristics. Thus, one of the foundational prerequisites to an assisted dying scheme is accessibility or equality of access. Concerns about inequitable access stem from a number of sources.

First, geographic differences and the unequal distribution of healthcare resources could place some Canadians in a situation where their options for healthcare providers and healthcare institutions are quite limited. This also limits their treatment choices and may adversely impact their opportunity to obtain assistance in dying. This is a concern to which provincial and territorial governments must be particularly sensitive, and may also have funding implications for the federal government. It is also a matter to be addressed by the national and provincial medical associations and licensing authorities.

Second, the legislative and regulatory scheme that is established (both at the federal and provincial levels) should not be so onerous that only those with high levels of education, significant family supports, and strong self-advocacy skills can benefit. In Oregon where assisted suicide has been legal for over 15 years, one study suggests that the beneficiaries of the law are overwhelmingly white, financially secure men, with a higher than average level of education. It is difficult to know why this is the case, but if those with less education and less confidence in asserting their rights are not able to obtain assistance in dying, our scheme will not be working as it should, and could be subject to further successful litigation.

Finally, in order to ensure that physician assisted dying is accessible, the medical services that make up this assistance must be covered under all provincial health insurance schemes. Ability to pay should not be a barrier to obtaining this service. Those who are suffering should not be made to suffer further because they cannot afford a service they deem vital and necessary.

4. Reconciliation of Rights

CCLA recognizes that while assistance in dying is intended to benefit the individual who wishes to end his or her life, those asked to provide assistance are also entitled to constitutional protection. Freedom of religion and conscience are protected by the *Canadian Charter of Rights and Freedoms* and the Court's decision in *Carter* explicitly recognizes that the *Charter* rights of patients and physicians will have to be reconciled.

Health care providers should not be required to assist individuals in dying if doing so would be contrary to their religious or conscientiously-held beliefs. At the same time, as noted above,

⁷ See e.g. *R. v. Morgentaler*, [1988] 1 S.C.R. 30.

⁸ Ronald A. Lindsay, "Oregon's Experience: Evaluating the Record" (2009) 9:3 The American Journal of Bioethics 19 at 22.

inequality of access to assisted dying is a genuine and significant concern. The conscientiously held objections of providers cannot bar their patients' access to medical assistance.

CCLA's position is that providers who object to assisting a patient end their life must provide referral information that is accessible to the patient and must facilitate any transfer of the patient's care. The Canadian Medical Association (CMA) has suggested that "a system should be developed whereby referral occurs by the physician to a third party that will provide assistance and information to the patient". CCLA takes the position that this is an acceptable compromise provided the third party can also provide an effective referral to another physician. However, if such a scheme is not established, CCLA believes that physicians should be required to provide an effective referral to patients.

In addition, health care providers or institutions that engage in tasks that are only remotely connected to the provision of assistance in dying (e.g. completion of basic paperwork, preliminary testing, etc.) should not, as of right, simply be able to opt out of providing these services for patients seeking assistance in dying. Where others can perform the task or an accommodation can be made without impacting on patient care, this should certainly be done. If this cannot be achieved, however, the patient's access to a service should, in CCLA's view, take precedence.

The reconciliation of patient and provider rights will be a matter for provincial licensing authorities (for physicians and other regulated health professions) to address clearly and decisively. Healthcare institutions must also consider the question of refusals and ensure that patient access is prioritized and transfer of care achieved as smoothly as possible. As previously stated, the provision of assistance in dying allows individuals some measure of control over when and how they die, and is not a stark choice between life and death. In order to ensure equality of access, publicly funded hospitals that provide palliative care or other end of life treatments should similarly provide assistance in dying, regardless of any institutional religious affiliation. If there are no physicians at such institutions who are willing to provide the service, the requirement for an effective referral would be engaged.

5. Accountability and Evidence-Based Assessments

The question of legalizing physician-assisted dying has been a controversial one for decades, and while the Supreme Court's decision clarified the law, it will nevertheless be important to maintain vigilance in monitoring how the new regime works. Tools must be put in place in order to monitor how the practice of physician-assisted dying is being carried out, who is using it, and any concerns of abuse or contravention of the law. The evidence gathered through this process

⁹ Canadian Medical Association, [Draft] *Principles-Based Approach to Assisted Dying in Canada*, p. A2-9, online: << https://www.cma.ca/Assets/assets-library/document/en/advocacy/EOL/care-at-the-end-of-life-cma-framework-june2015-e.pdf> (accessed 3 November 2015).

should be easily accessible to the public, in order to build and maintain confidence in the new system and assess opportunities for improvement or fine-tuning.

Federal and Provincial Responsibilities

There are roles for federal and provincial and territorial governments in regulating physician-assisted dying. CCLA believes that the federal government should act quickly to enact an exception to s. 241 of the *Criminal Code* and amend s. 14 of the *Criminal Code* in order to permit physician-assisted dying in certain circumstances. The exception must be crafted in a way that leaves the provincial and territorial governments with some leeway in determining the prerequisites to obtaining assistance and the safeguards to prevent abuse. ¹⁰

The formation of an interprovincial advisory panel on physician-assisted dying is an important development that CCLA supports. While each province and territory must legislate and regulate in line with its own objectives and policy environments, it is crucial that Canadians have equal access to this service across the country. Interprovincial cooperation is thus not only welcome, but necessary. CCLA acknowledges that the province of Québec has already legislated in this area and that *Bill 52: An Act respecting end-of-life care*, ¹¹ is already in force. Bill 52 provides a useful model for other provinces and was drafted following extensive consultations. At the same time, CCLA is concerned about certain aspects of the Bill, in particular the requirement that a patient may only receive medical aid in dying if he or she is "at the end of life" As described further above, this term may be unduly vague, there is no principled reason for the requirement, and it was not an explicit requirement established by the Supreme Court in *Carter*.

Provincial and territorial governments will also have to work with stakeholders within their provinces/territories including licensing bodies and medical associations to create clear and comprehensive regulation of physician-assisted dying.

Looking to a New Regime: Key Safeguards & Components

The Supreme Court of Canada's decision provided important clarifications about the requirements for a constitutionally compliant assisted dying regime. Assistance must be available to competent adults who are suffering intolerably due to a grievous and irremediable medical condition. These elements, laid out in the Supreme Court's decision, establish the minimum requirements for a new legal regime. The Court affirmed the lower court's determination that "the risks associated with physician-assisted death can be limited through a carefully designed

¹⁰ CCLA acknowledges that crafting an exemption under the *Criminal Code* that provides clear guidance but does not unduly restrict the provincial and territorial governments is a challenge. While CCLA does not endorse every aspect of the draft statute provided in Downie and Bern, *supra* note 5, it does provide a useful starting point to consider how this balance between the federal and provincial/territorial roles could be achieved.

¹¹ RSQ c S-32.0001.

¹² *Ibid.*, s. 26 (3).

and monitored system of safeguards." It is CCLA's position that the section 7 right to life, liberty and security of the person, requires a system of safeguards that operate to ensure that those who choose assistance in dying make an informed decision that is taken freely. Safeguards however, should not be used as obstacles or deterrents to those who are competent, suffering with a grievous and irremediable condition.

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A new legal regime around physician-assisted dying must address the following key considerations:

- a) **Informed Consent:** Both the common law and provincial statutes include laws regarding informed consent to medical treatment. The notion of informed consent suggests that patients are agreeing to a treatment proposed by a healthcare provider. With respect to assisted dying, it is anticipated that patients will be the ones making a request, highlighting the importance of autonomy in this particular treatment decision. However, it is equally important that patients have a full understanding of their underlying condition, their various treatment options, and opportunities for support. The nature of the information that will establish a truly informed decision could usefully be laid out in legislation or regulations.
- b) **Capacity:** Existing provincial law addresses questions of capacity to consent to treatment. Typically, there is a presumption of capacity and CCLA takes the position that this presumption should hold in the context of assisted dying. Where an objection, question or concern about capacity is raised by a health care provider or close friend or family member, a formal assessment of capacity should be required.
- c) Request for assistance: In the context of assisted dying, it is important to recognize that some individuals may have a limited ability to effectively voice their request or to sign a document attesting to it. The expression of an individual's wish to end their life should be clear and may be indicated in a manner that is appropriate to and commensurate with the individual's physical abilities. CCLA supports the use of witnesses when requests are made. However, excluding certain witnesses based on a close connection or the potential to benefit financially from the patient's death, while important to avoid conflicts of interest, could make it difficult for individuals to find willing witnesses. This should be addressed by healthcare institutions and providers.
- d) **Cooling off period:** A request for assistance in dying should be free of coercion and enduring. CCLA does not oppose requiring a <u>brief</u> waiting period between making a request and carrying out the act of assistance. The period should be long enough to allow for reflection, but not so long a painful illness becomes even more unbearable or serves to act as a deterrent or obstacle to obtaining assistance in dying. Any such period should be subject to exceptions where an individual's condition may be declining rapidly or where a patient has little time left. CCLA does not see the benefit

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¹³ Carter, supra note 1, para. 117.

- of requiring multiple requests for assistance before a patient can have access to the service.
- e) **Mature minors:** The Supreme Court's decision dealt with competent adults and did not address the question of children or adolescents. CCLA appreciates the concern about protecting minors, but notes that grievous and irremediable conditions do not discriminate by age. As a result, CCLA would support a regime that allows mature minors to request and receive assistance in dying. The concept of a mature minor recognizes that some young people have the capacity to consent to and refuse treatment (including life-saving treatment) where they demonstrate understanding of their medical condition and the consequences of treatment.¹⁴ In CCLA's view, there is no principled reason to distinguish between mature minors and competent adults.
- f) **Monitoring and reporting:** While health institutions and provincial ministries may wish to do their own monitoring and reporting of how physician-assisted death operates, a national monitoring body is, in our view, necessary. Only a national monitoring body will be able to assess equitable access. In addition, such a body could be empowered to report concerns about abusive practices to provincial regulatory bodies for investigation and potential discipline.

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¹⁴ A.C. v. Manitoba, 2009 SCC 30.