Fair Access while Protecting Vulnerable Persons:

Recommendations to the Special Joint Parliamentary Committee on Physician-Assisted Dying

Canadian Association for Community Living
February 1, 2016

The Canadian Association for Community Living (CACL) is a national federation with over 300 local associations, 13 provincial/territorial associations and over 40,000 members working to advance and safeguard the human rights and inclusion of persons with intellectual disabilities and their families.

Canadian Association for Community Living
Association canadienne pour l'intégration communautaire

Diversity includes. On se ressemble.

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Introduction

The relationship between the prohibition on assisted suicide, and its animating social purpose to protect life and guard against its taking, was fundamentally re-drawn in the Supreme Court of Canada decision in *Carter*. Much more than a new stop on the 'continuum of care', introducing a system for physician-assisted suicide and voluntary euthanasia (PAS/VE) requires a profound transformation of health and criminal law in Canada.

This transformation takes place at the dawn of an era where vulnerability and fragility will become more pervasive than ever before, by virtue of a rapidly growing proportion of Canadians with disabilities and older persons. Households, health care and community support systems, our social landscapes and cultural imaginations are all undergoing radical change as a result. We must not let the value of an individualist autonomy be our exclusive guide in this moment, or overtake the critical decisions Parliament must now make. We must use this opportunity to deepen our understanding of our fundamental interdependence, of an autonomy always lived in relationship, dependence, trust and care with others. It is only in a shared community of such understanding that we can greet the growing number of Canadians living vulnerable and fragile lives, with equal respect, dignity and inclusion.

These are the starting points for our recommendations.

Outline of Recommendations

The Supreme Court specified in *Carter* four legal criteria that must be met in authorizing requests for PAS/VE:

- An adult with a grievous and irremediable medical condition;
- Enduring suffering caused by the condition, and that is intolerable to the adult in the circumstances of his or her condition;
- Decisional capacity and legal competence to make the request and consent to the lethal substance; and
- Not being vulnerable to being induced to commit suicide in a time of weakness.

Under *Carter* **all four criteria must be met**. No criterion is more important than another. The system must have the procedures, the duties, and the criminal liabilities clearly defined and specifically laid out to ensure patients, physicians, and provincial-territorial health care authorities and regulators can comply.

Our recommendations to Parliament for this purpose are divided into three main sections:

A. Proposed definition of 'grievous and irremediable medical condition'
B. A robust safeguards system compliant with *Carter*
C. Restrictions on access – not through advance directives, nor to mature minors

A. Proposed definition of 'grievous and irremediable medical condition'

We recommend that Québec's Bill 52 provide the starting point for the definition of grievous and irremediable medical condition: incurable serious illness; advanced state of irreversible decline in capability; and, suffering from constant and unbearable physical or psychological pain which cannot be relieved in a manner the person deems tolerable.

In order to ensure compliance with the *Carter* decision, we also recommend adopting the clarifications in the definitions of 'grievous and irremediable medical condition' presented in the 'Draft Federal Legislation to Amend the Criminal Code to be Consistent with *Carter v. Canada (Attorney General)* 2015 SCC 5" prepared by David Baker and Gilbert Sharpe. The Draft defines these terms as follows:

- "Grievous" means a condition or disease experienced by a Patient who is at the end of life and in an advanced state of irreversible decline in capability, which notwithstanding the availability of insured services and quality of life care, is capable of causing constant and unbearable physical or psychological suffering which cannot be relieved in a manner that the Patient deems tolerable;
- "Irremediable" means a terminal disease that is incurable and has been medically confirmed by a Physician, and will by evidence-based medicine and using reasonable judgment, produce death.

We make this recommendation for five main reasons:

1. **Not defined by the Supreme Court but consistent with the trial decision**
   The definition is consistent with the trial judge's modification of the plaintiff's original definition, to include only those conditions that left the person in "advanced state of weakened capacities", with "no chance of improvement" and specific exclusion of those who are "clinically depressed" or whose source of intolerable suffering is "psychosocial" [at paras. 1390-91]. In granting the constitutional exemption to Ms. Taylor, the trial judge made explicit that a main criteria was that Ms. Taylor be "terminally ill and near death, and there is no hope of her recovering" [at para. 1414]. Although the Supreme Court of Canada did not define grievous and irremediable, the fact that it adopted the trial judge's terminology without comment, offers a strong inference that it found the trial decision definition and criteria valid. Otherwise, the Court would likely have altered or rejected it.
2. **Reflects the parameters of the declaration in the Supreme Court decision**
   Throughout its decision the Supreme Court stresses that the reasons for invalidating the total prohibition are grounded in circumstances like those of Ms. Taylor, and the Court explicitly rejects that conditions "such as euthanasia for minors or persons with psychiatric disorders or minor medical conditions", would fall "within the parameters suggested in these reasons." [para 111]
3. **Consistent with the policy objective of the prohibition and its 'animating social values'**

Both the Supreme Court of Canada and the trial judge quote *Rodriquez* to distinguish between the objective of the prohibition to protect persons who are vulnerable to being induced to commit suicide, and its underlying values. In its decision, the Supreme Court refers to "the preservation of life" as an "animating social value" underlying the objective (at para. 76). Justice Smith references the state interest in the protection of life and the *Charter* value that life should not be taken, to ground the objective of the prohibition (at para. 1190). To that end, she quotes Justice Sopinka's statement in *Rodriguez* where he reflects on the purpose served by the prohibition:

> "In upholding the respect for life, it may discourage those who consider that life is unbearable at a particular moment, or who perceive themselves to be a burden upon others, from committing suicide."[para. 608 in Rodriquez]

Thus, the exceptions to the prohibition should be strictly limited to end of life medical conditions. To provide state-sanctioned 'taking of life' of people with mental health, intellectual, cognitive or other disabilities, who do not otherwise have terminal conditions, would be a profound violation of these values. The value of autonomy is important, but it does not trump all other values that Canadians hold dear, and that we rely on our governments to protect.

4. **Provides clearer parameters for designing safeguards than a wide open definition would allow –** Absent the parameters provided in the Quebec legislation and the proposed amendments in the Baker/Sharpe draft, there would be significantly increased risk that persons who are vulnerable to being induced to commit suicide in a time of weakness would die wrongful deaths under the system. Clearly defining grievous and irremediable along the lines proposed by Baker and Sharpe provides the guidance needed in designing and managing a safeguards system, specifically with respect to: clinical diagnosis of grievous and irremediable conditions and attendant enduring and intolerable suffering; capacity assessment; the informed consent process; and, vulnerability assessment. This is a more cautious approach than some would advocate, but it is cautious for good reason and justified by the animating social values *Carter* recognizes.
5. **Strong public support and early adoption in Québec –** Extensive consultation and public dialogue in Quebec led to the eligibility criteria defined in Bill 52, and it was adopted by a large majority in the National Assembly. The data from the federal panel survey of almost 13,000 Canadians also suggests support for this approach. Depending on the question, an absolute majority or large plurality of respondents would restrict eligibility to life-threatening illness, and exclude mental health conditions.

B. A Robust Safeguards System Compliant with *Carter*

A safeguards system must achieve two policy objectives: 1) that adults have fair access to PAS/VE where legal criteria are met to justify an exception to the prohibition on assisted suicide; and, 2) that vulnerable adults are protected from being induced to access the system in order to commit suicide in a time of weakness. Core elements should include:

- **Assessment by two physicians, including an independent physician who is qualified by expertise regarding the patient's medical condition** to: diagnose the adult's medical condition; assess and address the suffering associated with it; present treatment options including all reasonable palliative care options; and assess risks of coercion and undue influence, the possibility of subtle influence, and the risks of unconscious biases.
- **Mandatory vulnerability assessment** to determine if factors unrelated to the medical condition are causing the suffering which motivates the request and, if so, what alternative courses of action could be considered. Such assessment must be designed to: screen for ambivalence; recognize the vulnerability of elderly persons to abuse and exploitation, recognize that persons with disabilities face prejudice and stereotyping; be alert to the risk of unconscious bias about the quality of life of a person with a disability; and require an assessment by a psychiatrist or registered psychologist where there are valid concerns a person is being induced or coerced, or questions about capacity.
- **Advance review and authorization** by an independent panel.

These core elements of a safeguards system are further outlined below. CACL has issued background papers on needed safeguards, including: "Assessing Vulnerability in a system for physician-assisted suicide and voluntary euthanasia."

Can proposed safeguards be justified under *Carter*?

The first question to consider is whether these proposed safeguards would be compliant with *Carter*. The trial judge's review of a large body of evidence points directly to need for each of these safeguard elements to be in place in order to protect vulnerable persons from being induced to commit suicide. Her conclusion that these safeguards *could* be established is affirmed in the strongest of terms throughout the Supreme Court decision.

There is an alternative view, which is that the Supreme Court concluded that the current capacity and consent processes in health care systems across Canada are sufficient safeguard to meet the two policy objectives. This seems a far too narrow and highly risky reading of the decision. If adopted as the basis for safeguards, as proposed by the 'Provincial-Territorial Expert Advisory Group (PTEAG) in its recommendation #20, it would almost certainly lead to the abuses the trial judge was convinced Canada could guard against. In fact, the Supreme Court clearly signals it will show deference to a complex and robust safeguards system established by Parliament, that:

- Responds to the complex social policy issue raised by PAS/VE; [at para. 98]
- Weighs and balances the perspective of those who might be at risk against that of those who seek assistance in dying; [at para. 98]
- Imposes "stringent limits that are scrupulously monitored and enforced"; [at para. 105]
- Legislatively restricts discretionary power of oversight mechanisms; [at para. 113]
- Is carefully monitored; [at para. 117]
- Does not invite abuse by making impotent criminal sanction against the taking of lives; [at para. 120] and,
- Fulfills a complex regulatory scheme created by Parliament. [at para. 125]

The Supreme Court arrives at these findings by accepting the trial judge's evidence and conclusion that a system with "properly designed and administered safeguards was capable of protecting vulnerable people from abuse and error" and quotes the trial decision (at para. 105) to this effect:

> My review of the evidence […] leads me to conclude that the risks inherent in permitting physician-assisted death can be identified and very substantially minimized through a carefully-designed system imposing stringent limits that are scrupulously monitored and enforced. [para. 883]

To arrive at her conclusion, the trial judge reviewed jurisprudence including the *Rodriguez* majority decision and dissenting opinions, expert evidence, as well as the safeguards proposed by the plaintiffs in *Carter*. She points to an array of safeguards from these sources that she finds could address concerns about competence, voluntariness, informed consent, ambivalence and socially vulnerable individuals. In summary form, and for example, these include:

- **Properly-qualified and experienced physicians** who can reliably assess patient competence in the context of life-and-death decisions, "so long as they apply the very high level of scrutiny appropriate to the decision and proceed with great care." [para. 798]
- **Clinician awareness of the risks of coercion and undue influence**, of the possibility of subtle influence, and of the risks of unconscious biases regarding the quality of the lives of persons with disabilities or persons of advanced age." [para. 815]
- **Requirement to consider a range of treatment options** including all reasonable palliative care interventions, including those aimed at loss of personal dignity. [para. 831]
- **Screening for ambivalence**, by assessing capacity and requiring some time to pass between the decision and its implementation. [para. 843]
- **Assessment procedures which recognize that elderly persons are vulnerable** to abuse and that the assessment of voluntariness of elderly people must incorporate an understanding of that reality. [para. 847]

- **Assessments by qualified physicians who recognize that persons with disabilities face prejudice and stereotyping** and who are alert to the risk of unconscious bias about the quality of life of a person with a disability. [para. 853]

Justice Smith draws on the same sources to show how these safeguards could be instituted. In presenting the evidence, Justice Smith acknowledges: "This review of the evidence permits no conclusion other than that there are risks inherent in permitting physician-assisted death, and that the utmost care would be needed in designing and managing a system which would allow it, in order to avoid those risks." [para. 854] Again, in summary form, the evidence points to the following kinds of mechanisms:

- **Second opinion required –** The vetting process should require a second opinion regarding consent in all cases. This second opinion might involve a referral to a psychiatrist but might also be provided by a general practitioner or by a specialist in another field, as appropriate. [para. 855]
- **A defined, legal process to prevent coercion**, in order to protect those who are vulnerable and to make sure we are doing it for physical terminal illnesses and the attendant intractable physical, psychological and spiritual suffering, and excluding those with chronic mental illnesses. [para. 855]
- **Competence certified in writing by a treating physician and by an independent psychiatrist**. [para. 859]
- **Physician certification of terminal illness** and near death, no hope of recovery, suffering unbearable physical pain or severe psychological distress. [para. 859]
- **Prior and post review** to avoid abuse. [para. 864]

Justice Smith also presents the safeguards recommended by the plaintiffs in *Carter* including their recommendation for prior review and approval of requests and recommendations by physicians. The trial judge notes that the plaintiffs put their recommendations forward to "illustrate that less drastic means than a blanket prohibition are available to achieve Parliament's objective in a real and substantial manner." [para. 882] These include (at paras. 873-881):

- **mandatory psychiatric evaluation** for informed consent carried out at the highest degree of scrutiny
- **disqualification of Major Depressive Disorder**;
- a **minimum waiting period**;
- confirmation of the patient's diagnosis, prognosis, and treatment alternatives by **an independent physician** who is qualified by expertise or experience regarding the patient's illness;
- **required palliative care consultation** with a physician who has expertise in palliative care;

- the physician and second physician must each be required to provide a report to an **expert review panel** that must consist of an ethicist, a lawyer and a doctor;
- within 48 hours of receiving the reports, the panel must review them for accuracy and adequacy of information, **and indicate whether they approve of the reports**.
- **patient right to appeal expert panel decision**, directly to the provincial Superior Court.

The trial decision and the Supreme Court decision in *Carter* give substantial scope for designing a robust safeguards system. The evidence shows they are entirely justified and compliant with *Carter* given the objective of the prohibition and underlying values. Drawing on these sources, and based on our analysis of risks to vulnerable persons, we strongly recommend *Criminal Code* provisions include:

1. **Clear standard for physician duties**
   - undertake clinical diagnosis that clearly determines if medical criteria are met, consistent with the parameters set out in the *Criminal Code*
   - take all reasonable steps to inquire into the causes of the patient's suffering and to provide options to address the causes;
   - assess capacity to make a request for PAS/VE in the circumstances, including requirements to ensure all reasonable alternative courses of action are explored including palliative options, that relevant information is provided, and the patient can demonstrate and express understanding and appreciation of the nature and consequences of the decision, and the refusal of any alternative courses of action, if that is the case;
   - prepare and provide reports, assessments, and other materials as may be needed, and including a vulnerability assessment, to accompany the patient's application to the review board considering the request.
   - ensure other health care professionals are engaged as may be needed to fulfill these duties and meet the *Criminal Code* requirements for responding to requests for PAS/VE.
2. **Mandatory vulnerability assessment**
   - Must be undertaken in response to each request in a manner and with valid procedures to determine if factors that could induce the patient to commit suicide in a time of weakness are motivating the request for PAS/VE. If such factors are identified, the physician(s) must:
     - take all reasonable steps to assess suicide risk and patient safety needs
     - take any steps required to prevent suicide, and ensure the patient's safety and well-being;
     - determine whether such factors impair the patient's competence to consent.
     - engage a multi-disciplinary health team as may be required for these purposes.
   - Where either physician is concerned that the patient requesting PAS/VE may also have a mental illness or disorder, a psychiatrist must be engaged to assess whether a psychiatric condition exists and, if so, whether it is impairing the adult's insight, cognition or

judgment. The psychiatrist must provide a separate opinion to the review board on this matter, including whether capacity is sufficiently impaired by the psychiatric condition to render the adult unable to consent, and should be denied access on the principle of beneficence.

3. Advance review and authorization by an independent panel

- The need for an advance independent review mechanism has been recognized in international law by the Treaty Body for the *International Covenant on Civil and Political Rights*, ratified by Canada in 1976. In its 2009 'Concluding Observations' on reports from the Netherlands, the United Nations Human Rights Committee, Treaty Body for the *Covenant,* states:

  > The Committee remains concerned at the extent of euthanasia and assisted suicides in the State party. Under the law on the Termination of Life on Request and Assisted Suicide, although a second physician must give an opinion, a physician can terminate a patient's life without any independent review by a judge or magistrate to guarantee that this decision was not the subject of undue influence or misapprehension. (art. 6).

  The Committee reiterated that its previous recommendations, made in 2001, calling for "independent review by a judge or magistrate" because of the potential for violation of the "inherent right to life" as recognized in Article 6 of the *Convention.* [1]
- There is also strong public support. Key among the findings of the 'Federal External Panel on Options' is that among the almost 13,000 respondents to its survey, 53% supported the establishment of an external mechanism to ensure that every request for physician-assisted suicide meets legal requirements. In a more recent poll by the Canadian Association of Retired Persons, 54% supported review by an independent review board, if review of each case were required.
- Proposed provisions for advance review and authorization are presented in "Draft Federal Legislation to Amend the Criminal Code to be Consistent with Carter v. Canada (Attorney General) 2015 SCC 5" prepared by David Baker and Gilbert Sharpe. It may be feasible to expand the mandate of the current Review Board's as proposed in that Draft.
- Alternatively, the *Criminal Code* could be amended to establish or designate separate review boards along the lines of those now provided for in section 672.38 of the *Code*. Provisions could require that a Review Board be established or designated for each province and territory to receive, consider and approve or deny applications for PAS/VE. Whether or not a judge was required would need consideration. Members appointed to the boards, and to rosters to be available for application reviews as needed could include judges, physicians, lawyers, bio-ethicists and public members. Under this approach, for example, the current Ontario Consent and Capacity Board could be designated for this purpose, provided it met the provisions set out in the *Code*.
- Whatever review board mandate, authority and structure is established, it must be designed to ensure consistency, transparency and fairness across all provinces and territories.

- Some have suggested that any such review boards would unnecessarily obstruct access, and point to the Supreme Court's decision in *Morgentaler* to buttress this point. It is important to note that *Morgentaler* did not find that the therapeutic abortion committees were invalid under criminal law. The problem was that they were not designed or implemented in a manner that ensured fair access. As the Supreme Court stated: "When the decision of the therapeutic abortion committee is so directly laden with legal consequences, the absence of any clear legal standard to be applied by the committee in reaching its decision is a serious procedural flaw." Parliament can use the *Criminal Code* to guard against such flaws and ensure review panels make decisions expeditiously.
- CACL believes such a mechanism is essential, not only as a check to ensure physicians have fulfilled their duties, given the social values at stake. As importantly, it will clearly distinguish the between the roles of providing health care, and the authorizing of an intervention intended to bring about the death of a person. Thus, it will help to protect the integrity of the health care system. A physician's job is "never to throw in the towel" as one ethics director in a cancer care centre advised us. Separating out these roles may provide more physicians with confidence they can attend to their patients' suffering without violating their ethics. It will also help to build Canadians' trust in their health care system as this transformation is introduced.

C. Restrictions on Access – Advance Directives and Mature Minors

1. Do not provide access by advance directive

- *Carter* is crystal clear: the patient ***must be capable <u>in the circumstances</u> of his or her condition***. This requires that a person must have capacity to consent to taking the dose that will trigger death, at the time it is administered. This means there is no room for advance directives. Parliament should clearly assert this in the legislation.
- ***We cannot predict into the future either what those circumstances might be***, or how our future selves might suffer. Researchers call this the problem of "affective forecasting" in the area of living wills, and have found that when people actually arrive at the state their past selves imagined, even when quality of life is low, they almost unanimously want to eke out more time. [2]
- Advance directives ***<u>do not have equal moral authority</u> to the decision of a capable adult in the current moment***. Ethicists say the reasons are: 1) the future may hold "radically altered circumstances" and so a pre-determined decision cannot be binding; 2) "therapeutic options and hence prognosis can change over time; and, 3) "individual's interests" can change in unforeseen and unpredictable ways, which means a person can fail to appreciate the pleasures that might be found in a future, unexpected life.[3]
- An ***advance directive made for withdrawal of treatment is ethically completely different*** than one for PAS/VE. The former requires that a health care provider stop an

intervention at a specified 'triggering' point when a person is no longer able to consent, because we have a right not to have our bodies interfered with. Not to respect that directive can constitute criminal assault. It is an entirely different matter, ethically and legally, to direct in advance that health care providers administer substances intended to terminate the life of a person who is unable to consent. For Parliament to provide authority for advance directives, would entirely undermine a vulnerable persons' inherent right to life, and go far beyond the very strict exceptions *Carter* allows.

- There are concerns that without provision for advance directives, people may request PAS/VE and die earlier than they otherwise would have. We believe this would be a tragic outcome of the right to PAS/VE that Canadians now have in certain circumstances. But we must go to the underlying cause and heart of this problem. Canada lacks the desperately needed national strategies and investments in palliative care, home care and disability supports that the majority of Canadians are calling for in response to the *Carter* decision, as we see in the poll conducted by the Federal Panel. Especially in the wake of *Carter,* Canadians need clear messages from Parliament: that living with neurological conditions or diminishing cognitive or physical capacities need not be a reason to die; that vulnerable persons and their family caregivers will be supported; that caring, interdependence and changing, even declining, capacities are part of how we see good lives being lived in this country; and, that Canada safeguards both the right to autonomy and the right to life, dignity and inclusion, regardless of one's vulnerabilities.

2. Restrict access to those 18 and over

There has been much discussion of whether *Carter* justifies defining 'adult' to include mature minors. CACL strongly recommends against this inclusion, for the following reasons:

- Nowhere does the trial decision, the Supreme Court decision, or the Supreme Court order extending the stay of invalidity, anticipate or consider this expansion. *Carter* makes explicit that PAS/VE "for minors or persons with psychiatric disorders or minor medical conditions", "would not fall within the parameters suggested in these reasons."
- As University of Toronto law Professor, Trudo Lemmens has stated on this question, "In other areas of social life, including areas related to health care and public health protection, and the right to vote, we do have specific age limits that restrict decision making, including the age for buying tobacco and alcohol, or age limits in relation to gamete donation and surrogacy under the *Assisted Human Reproduction Act*. In *A.C. v Manitoba* the Supreme Court explicitly recognized that for decisions that are associated with more risk, a more careful and comprehensive scrutiny is necessary. Treating mature minors differently is, in other words, compatible with the Charter."[4] We accept that the breadth of experience gained over that lifespan is an essential feature of capacity to make certain legal decisions. We firmly believe that the same rationale applies to this decision, and even more so given what is at stake – the state-sanctioned taking of life.

Conclusion

At this critical moment in our history, we appeal to you as Parliamentarians to embed in the *Criminal Code* the safeguards needed for both fair access *and* assured protection of vulnerable persons. Provincial/territorial health authorities and regulators, physicians, and other health professionals need clearly and unequivocally stated legal requirements to ensure their policy and program development is compliant. Just as importantly, patients, families, loved ones and caregivers need to fully understand their rights and obligations, as they face among the most difficult decisions of their lives. Our recommendations are informed by all these concerns and, in particular, by people with intellectual disabilities and their families who understand deeply what it means to live in vulnerability and aspire to inclusion.

Endnotes

[1]U.N. Human Rights Committee, *Consideration of Reports Submitted by States Parties Under Article 40 of the Covenant*, para. 7, U.N. DOC. CCPR/C/NLD/CO/4 (Aug. 25, 2009). *See also* U.N. Human Rights Committee, *Concluding Observations of the Human Rights Committee: Netherlands*, para. 5–6, U.N. DOC. CCPR/CO/72/NET (Aug. 27, 2001).

[2] Brett Pellam (2004), "Affective Forecasting: The Perils of Predicting Future Feelings", Psychological Science Agenda, American Psychological Association (online: http://www.apa.org/science/about/psa/2004/04/pelham.aspx).

[3] See Allen Buchanan and Dan Brock (1989), *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge: Cambridge University Press), pgs. 103-107.

[4] Provided through personal communication from University of Toronto Law Professor, Trudo Lemmens, who has also presented to the Special Joint Committee on Physician Assisted Death.