

Lawyers

**SUBMISSION OF THE ADVOCACY CENTRE FOR THE ELDERLY TO THE
JOINT SPECIAL COMMITTEE ON PHYSICIAN-ASSISTED DYING**

February 2, 2016

The Advocacy Centre for the Elderly ("ACE") is pleased to provide comments on the appropriate legislative response to *Carter v. Canada (Attorney General)* (*Carter*)¹ based upon our extensive experience advocating for older adults in Ontario and our expertise in the areas of elder law, health law and end-of-life decision-making.

After providing a brief introduction to ACE, we will examine the following issues raised by *Carter* and the implementation of physician-assisted dying:

- Issues in ascertaining voluntary and informed consent to physician-assisted dying; and,
- Appropriate safeguards to ensure consent has been obtained prior to physician-assisted dying being administered, including an independent review of the decision, a vulnerability assessment and a prohibition on advance directives or substitute consent to physician-assisted dying.

We thank you for the opportunity to provide our submissions in this regard. ACE would be happy to participate in any further consultations, appearances or discussions with the Committee if invited to do so.

The Advocacy Centre for the Elderly

Established in 1984, ACE is a specialty legal clinic under the Ontario *Legal Aid Services Act*. It is the first and oldest legal clinic in Canada with a specific mandate to provide a range of legal services to low-income older adults. ACE's legal services include individual and group client advice and representation, public legal education, community development and law reform activities.

¹ 2015 SCC 5

ACE routinely advises families of critically ill hospital patients on end-of-life decision-making issues. ACE also intervened at the Supreme Court of Canada on *Cuthbertson v. Rasouli*,² which concerned end-of-life decision-making.

ACE staff have extensive experience in issues related to health care consent, and have been involved in many of the law, policy, and education initiatives relating to these issues in Ontario over the last 30 years. These have included:

- Participating as a member of the Fram Committee, the work of which resulted in the passage of Ontario's *Consent to Treatment Act, 1992*, and related legislation, including the *Health Care Consent Act, 1996*;³
- Acting as one of the principal authors of the training materials for health care professionals produced as part of two of the Alzheimer Society of Ontario initiatives on *Physicians' Education* (Initiative #2) and *Advance-Directives on Care Choices* (Initiative #7);
- Participating in the Ontario Medical Association *President's Advisory Committee on Palliative Care and Advance Care Planning*;
- Participating currently in the Advisory Committee for the Law Commission of Ontario Project on *Legal Capacity, Decision-Making and Guardianship*;
- Engaging presently, and for the past two years, in a number of educational initiatives for health care practitioners on health care consent and advance care planning. These initiatives, with several of the Local Integrated Health Networks in Ontario, have involved interactive, detailed training sessions as well as the production of an online training course on health care consent and advance care planning;
- Co-authoring, with the law firm of Dykeman Dewhirst O'Brien LLP, a major research paper for the Law Commission of Ontario entitled *Health Care Consent and Advance Care Planning in Ontario*;⁴ and,
- Providing comments on the College of Physicians and Surgeons of Ontario policies on end-of-life care, including its *Interim Guidance on Physician-Assisted Death*.

Given our years of practical legal experience and policy-development work on health law and other related policy issues that affect older adults in Ontario and across Canada, we trust that our comments on any legislative response to physician-assisted dying will be of some assistance.

² 2013 SCC 53

³ *Health Care Consent Act, 1996*, S.O. 1996, c. 2, Sched. A (HCCA)

⁴ Judith Wahl, Mary Jane Dykeman and Brendan Gray, *Health Care Consent and Advance Care Planning in Ontario: Legal Capacity, Decision-Making in Guardianship*, Law Commission of Ontario: January 2014, available at: <http://www.lco-cdo.org/capacity-guardianship-commissioned-paper-ace-ddo.pdf>

1. Issues in Ascertaining Voluntary and Informed Consent to Physician-Assisted Dying

Our comments below are based on extensive case work, client reports and experience conducting educational seminars for lawyers and health care providers with respect to health care consent and end-of-life decision-making. Through these experiences, ACE has observed that many health care providers often inadvertently fall afoul of Ontario law on health care consent generally, and around end-of-life decision-making issues in particular.

In Ontario, the *Health Care Consent Act, 1996*, provides that the following elements must be met for consent to be considered valid: (i) the consent must relate to the treatment; (ii) the consent must be informed; (iii) the consent must be given voluntarily; and (iv) the consent must not be obtained through misrepresentation or fraud.⁵

These elements of consent are required for all treatment decisions. Since the consequences of physician-assisted dying are irremediable, these elements must be strictly complied with to ensure that patients making this request provide legally valid informed consent.

ACE has significant concerns about the voluntariness of consent to physician-assisted dying. Voluntariness in this circumstance is nuanced and not easily assessed. In our experience, persons who experience multiple disadvantages may be more susceptible to undue influence and pressure. Persons with grievous or irremediable medical conditions and who also experience discrimination due to age and other overlapping factors may be particularly vulnerable.⁶ This may be due to a feeling that they are a burden on others as they lose their independence; social isolation; or fear of not having adequate social supports and medical resources to meet their needs. Any of these may be perceived as inducements toward physician-assisted dying. The result may be the person making their decision, not based on their suffering resulting from their illness or their own view of quality of life, but rather based on external pressures and fears about the availability of care at their end of life.

In addition, ACE is concerned that physicians who are assessing the voluntariness of their patients' consent to physician-assisted dying might not necessarily have the requisite expertise to do so. There is a lack of consistency between physicians assessing this element of consent. Not all physicians are typically trained in recognizing undue influence, lack of access to supports, dependency, social isolation or caregiver coercion or abuse. Several physicians' groups consulted in the *Final Report on Consultations on Physician-Assisted Dying* of the External Panel on Options for a Legislative Response to

⁵ HCCA, *supra*, note 3, s. 11 (1).

⁶ Parliamentary Committee on Palliative and Compassionate Care, *Not to be Forgotten: Care of Vulnerable Canadians*, (November 2011), available at:

https://www.mcgill.ca/palliativecare/files/palliativecare/parliamentary_report_eng_dec_2011.pdf

Carter v. Canada indicated that they too are concerned about the physician's ability to assess aspects of voluntariness such as coercion or to recognize the subtle signs of elder abuse.⁷

Furthermore, if the physician is solely given the burden to ensure that consent to physician-assisted dying is voluntary, it would mean that the physician has to wear multiple, conflicting hats: (i) treating the patient for underlying health conditions; (ii) discussing the option of physician-assisted dying with the patient; (iii) assessing capacity for physician-assisted dying; (iv) administering physician-assisted death; and (v) if the patient changes his/her mind about physician-assisted dying, possibly continuing to provide medical treatment. The physician may also face competing pressures from the institution in which he/she works, including allocation of beds or resources. These cumulative roles may compromise the physician in making legal determinations as to whether a patient is eligible for physician-assisted dying.

Lastly, older persons often experience barriers in the social environment in which aging takes place, resulting from the attitudes of service providers.⁸ Older adults with disabilities, who may have more contact with health care providers, often meet with negative attitudes while accessing health care services. At ACE, we frequently encounter situations where treatment is affected based upon assumptions related to age. For example:

- Older adults are constantly being asked about their "do-not-resuscitate" status, even when attending for a routine procedure;
- Older adults may be encouraged to forego or discontinue treatments due to age;
- Older adults are often not offered the same access to rehabilitative treatments and therapies as younger persons;
- Older adults may not be offered life-saving treatments such as chemotherapy or antibiotics, because of a diagnosis of dementia, for instance; and,
- Older adults are not referred to psychiatrists or psychologists because depression, anxiety disorders and dementia are considered a normal part of the aging process.

These incidents are indicative of a discriminatory attitude on the part of some health care providers and a biased evaluation of the older adult's quality of life, which contribute to feelings of invisibility and social isolation on the part of older adults.⁹

⁷ External Panel on Options for a Legislative Response to *Carter v. Canada*, *Final Report on Consultations on Physician-Assisted Dying of the External Panel on Options for a Legislative Response to Carter v. Canada* (December 15, 2015), available at: <http://www.justice.gc.ca/eng/rp-pr/other-autre/pad-amm/pad.pdf>, P. 70

⁸ Ontario Human Rights Commission, *Discussion Paper: Discrimination and Age- Human Rights Issues Facing Older Persons in Ontario*, (2000) available at: <http://www.ohrc.on.ca/en/discussion-paper-discrimination-and-age-human-rights-issues-facing-older-persons-ontario/specific-issues-facing-older-persons>

⁹ *Revera Report on Ageism* (2014), available at: http://www.reveraliving.com/about-us/news/publications/report-on-ageism-%281%29/report_ageism

ACE is deeply concerned that stereotypical, biased and discriminatory attitudes may enter the calculus when physician-assisted dying is being considered in relation to older adults. These biases may affect older adults by acting as a barrier to requesting physician-assisted dying. For example, an older adult with dementia may be dismissed as being incapable of consenting to physician-assisted dying without even being assessed. Such biases may also lead to health care providers not conducting as fulsome a review of the nature of the older adult's consent owing to preconceived notions regarding an older patient's quality of life. Without checks and balances such as independent assessments to root out these biases, they will go undetected.

2. Appropriate Safeguards to Ensure Consent has been Obtained Prior to Physician-Assisted Dying being Administered

The Supreme Court of Canada in *Carter* has asked that the legislature craft a response to its decision which balances "the autonomy and dignity of a competent adult who seeks dying as a response to a grievous and irremediable medical condition" with the "sanctity of life and the need to protect the vulnerable."¹⁰ ACE strongly believes that a system of safeguards must be put in place to ensure that an appropriate balance is struck. However, the regime advocated by the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying would not provide adequate protections.¹¹

i. The Two-Physician Model

The Provincial-Territorial Expert Advisory Group advocates a model where physician-assisted dying is first discussed with an attending physician who would be responsible for providing the patient with all other therapeutic possibilities. This physician would then assess the eligibility criteria with respect to the patient. Next, a reviewing physician would provide a second opinion on the eligibility criteria and provide a report to the attending physician. Once the request is approved and the patient confirms the request, physician-assisted dying is either administered or the means are provided. The death is reported to a review committee which may report to a pan-Canadian oversight body.¹²

The Provincial-Territorial Expert Advisory Group felt that assessment by a second physician was a "justifiable hurdle, and not an unjustifiable barrier." Part of the rationale was that as health care providers conduct such assessments on a regular basis and in complex decisions, these same skills would be sufficient for assessing physician-assisted dying.

Respectfully, ACE disagrees with this analysis. In our practice, we have noted that not all health care providers are able to assess voluntariness or are proficient in the law on

¹⁰ *Carter*, *supra*, note 1, at 2

¹¹ Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying: Final Report (November 30, 2015), available at: http://www.health.gov.on.ca/en/news/bulletin/2015/docs/eagreport_20151214_en.pdf

¹² *Ibid.* at p. 61

health care consent. The irremediable consequences of physician assisted dying warrants additional safeguards, as is recognized by the fact that a second physician's opinion is required even in the model advocated by the Provincial-Territorial Expert Advisory Group.

ii. ***Vulnerability Assessment***

ACE submits that the two-physician model does not recognize the limitations often faced by physicians when attempting to assess the voluntariness of a decision. As discussed above, physicians are not trained in ensuring that a decision is free from undue influence, coercion, and fear about becoming a burden or addressing their own unconscious biases.

Such issues could be avoided if an assessment of vulnerability was completed as proposed by the Canadian Association for Community Living (CACL).¹³ Similar to the two-physician model, CACL proposes that the attending physician conduct an initial assessment of whether the person is suffering from a "grievous and irremediable health condition." This physician would also be responsible for determining whether the patient is capable of consenting to physician-assisted dying. In Ontario, the capacity to consent to treatment test is as follows:

A person is capable with respect to a treatment, admission to a care facility or a personal assistance service if the person is able to understand the information that is relevant to making a decision about the treatment, admission or personal assistance service, as the case may be, and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.¹⁴

A similar test would be applied to determine whether patients requesting physician-assisted dying have the capacity to consent to this option.

In the CACL model, however, a specialized vulnerability assessor would be responsible for conducting a vulnerability assessment. This person would be trained in a variety of assessment tools in order to ascertain if issues other than the suffering caused by the person's grievous and irremediable medical condition would be the basis of the request for physician-assisted dying.¹⁵ Such specialization was advocated by Justice Smith in the trial decision in *Carter*, when she indicated that a capacity assessment would provide adequate safeguards:

¹³ Canadian Association for Community Living, *Assessing Vulnerability in a system for physician assisted suicide and voluntary euthanasia in Canada*, (January 2016) available at:

<http://www.cacl.ca/sites/default/files/uploads/CACL%20-%20Vulnerability%20Assessment%20in%20PAS-VE.pdf>

¹⁴ HCCA, *supra*, note 3, s. 4(1)

¹⁵ CACL, *supra*, note 13 at p. 28

. . . To be accurate and reliable, clinicians who perform such assessments would have to be aware 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.¹⁶

CACL also advocates further inquiry through a multidisciplinary assessment where a person is determined to be vulnerable to external factors when making a decision on physician-assisted dying. If, after this "stage two" assessment, a person is determined to be a high risk of being induced "to commit suicide for reasons other than the suffering caused by the medical condition", then they are refused physician-assisted dying.¹⁷ Importantly, this would include a process by which these refused patients could obtain assistance in addressing their vulnerability, such as being provided with additional service provision or involving government agencies, so that these persons are not simply abandoned.

This process would therefore require that experts conduct the analysis of voluntariness to ensure, firstly, that perceived vulnerabilities were not preventing access to physician-assisted dying for some and, secondly, that consent to physician-assisted dying was truly voluntary and patients were not being unduly influenced to take this option. Further, this vulnerability assessment would be ordered in respect of all persons rather than just persons with perceived vulnerabilities, thereby capturing persons whose vulnerabilities were not immediately apparent. The assessment would protect patients whose vulnerabilities were a result of ageism, discriminatory attitudes or subtle influences that might not always be visible.

iii. *Independent Panel*

ACE also recommends that rather than having a second physician assess the eligibility of a patient for physician-assisted dying, an independent administrative panel confirm that a person is eligible for physician-assisted dying. While the two-physician system advocates a review body, this body is intended to conduct a post-hoc review and therefore is completely ineffective as a safeguard against unwarranted physician-assisted death.

Justice Smith in the trial decision specifically points to other mechanisms which act to protect against coercion or pressure. Justice Smith specifically provides an example from Oregon, one of the states which have legislation on physician-assisted dying:

Nevertheless, Dr. Ganzini states the opinion that these risks are minimized in a number of ways:

. . . Second, there are neutral observers built into the process. For example, most patients are cared for by a hospice association (85-90% of

¹⁶ *Carter v. Canada (Attorney General)*, 2012 BCSC 886 at 815

¹⁷ CACL, *supra*, note 13 at p. 31

all PAS [Physician-Assisted Suicide] deaths in recent years) and the hospice personnel are aware of the request for PAS. As reported in study 16, patients who request PAS are routinely discussed among hospice workers and reviewed in the interdisciplinary team meeting. . . .¹⁸

However, not all persons in Canada requesting physician-assisted dying have the chance to hear from neutral observers. Ensuring that an administrative panel offers an interdisciplinary perspective to establish that the person is truly eligible can offer that chance. The panel would hear from the physician and the patient and would ensure consistency in decision-making. This administrative panel can also be responsible for ensuring that data about physician-assisted dying is maintained.

This proposal has been recommended by many parties, including the Council of Canadians with Disabilities, Canadian Association for Spiritual Care and the Canadian Psychiatric Association.¹⁹ The Canadian Psychiatric Association has made the further point that “such panels would help protect the therapeutic alliance between the individual and a clinician by eliminating any obligation on the clinician to decide whether the individual meets eligibility criteria.”²⁰ This separation would ensure that physicians are not forced into both the decision-making role for eligibility for physician-assisted dying as well as the role of caring for the patient.

The implementation of the board itself need not be onerous. In Ontario, the Consent and Capacity Board, an administrative law body created under the auspices of the *Health Care Consent Act*, makes decisions about many capacity-related issues, including treatment, long-term care home admission, and involuntary admission under the *Mental Health Act*. Specifically, as part of its authority under the *Health Care Consent Act*, Consent and Capacity Board already hears cases regarding end of life related to substitute decision maker’s authority.²¹ The Board must conduct hearings within seven days of the receipt of an application unless parties agree to a postponement.²² The hearings are expected to be conducted at the place where the patient resides or is receiving treatment. A similar panel could offer adequate safeguards and retain flexibility to ensure that the patient’s request was heard without burdensome procedural barriers and in a timely manner.

iv. No Advance Directives/Substitute Consent

The Supreme Court of Canada’s decision in *Carter* is quite clear that requests for and consent to physician-assisted dying cannot be made through a substitute decision-maker, but only by a competent patient.²³ However, as has been expressed in other venues, the decision can be considered a floor, not a ceiling. It is open to Parliament to decide to extend consent to physician-assisted dying not only to competent patients but

¹⁸ *Carter*, *supra*, note 16 at 436

¹⁹ External Panel on Options for a Legislative Response to *Carter v. Canada*, *supra*, note 7 at p. 95

²⁰ *Ibid.*

²¹ *HCCA*, *supra*, note 3, s. 54.

²² *Ibid.*, s. 75(2)

²³ *Carter*, *supra*, note 1 at 4

also through advance directives or based on substitute consent. ACE strongly advocates against having consent to physician-assisted dying being granted through any means other than a capable patient directly.

Allowing for substitute consent means that a patient's life may be ended without their consent. In Ontario, a substitute decision-maker can make health care decisions for a patient where the patient is incapable of making the decision themselves.²⁴ The substitute decision-maker must make decisions in accordance with the incapable patient's wishes, made while capable, or if there are no wishes applicable in the circumstances or it is impossible to comply with the wish, the substitute decision-maker must act in the incapable person's best interests.²⁵ Substitute decision-making is available in other end-of-life contexts such as withdrawal of nutrition or removing a person from a ventilator. However, if the ability of evoking physician-assisted dying where a patient is not terminal, allowing for substitute consent in this circumstance would create the potential for greater abuse. Further, there is a chance that the biases of the substitute decision-maker will influence the decision-making rather than the wishes of the patient themselves. The Provincial-Territorial Expert Advisory Group has advised against substitute consent to physician-assisted dying.²⁶

Nevertheless, the Provincial-Territorial Expert Advisory Group has indicated that a request for physician-assisted dying through a "valid patient declaration form" made following a diagnosis of a grievous and irremediable health condition may be fulfilled when suffering becomes intolerable. However, where a person is not yet experiencing intolerable suffering, such a document could be considered an advance directive.

Although some jurisdictions in Canada permit the use of advance directives, in Ontario, consent to treatment cannot be obtained vis-a-vis an advance directive. A person cannot communicate instructions on their future care directly to a health care provider unless the patient is providing consent regarding their present health condition. In the case of physician-assisted dying that may mean that the individual has "a grievous and irremediable health condition that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition."²⁷

In Ontario, if a person has communicated instructions about future care that are not in respect of their present health condition, such instructions regarding care are called wishes.²⁸ If a patient expressed a capable wish with regard to a particular treatment, and subsequently became incapable, the wish is to be interpreted by the substitute decision-maker and conveyed to the health care provider.²⁹ Therefore, even if wishes were written

²⁴ *HCCA, supra*, note 3, s. 20(1)

²⁵ *Ibid*, s. 21(1)

²⁶ Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying, *supra*, note 11, p. 32, Recommendation 14

²⁷ *Carter, supra*, note 1 at 4

²⁸ *HCCA, supra*, note 3, s. 5

²⁹ *Ibid*, s. 21(1)

down in a document such as a patient declaration form, which is permitted in Ontario law, these wishes could not inform a health care provider directly. Instead, the health care provider must **always** seek consent from a substitute decision-maker.

Given the differences in law on substitute consent in the provinces and the recognized potential for abuse, noted above, Parliament should not seek to stray from the guidance provided by the Supreme Court and that only capable persons can consent to physician-assisted dying.

Conclusion

The introduction of physician-assisted dying into the Canadian health care system presents profound challenges for all involved. Appropriate safeguards must be put in place at all levels to ensure that a balance is struck between access to the option of physician-assisted dying and protection of vulnerable persons from pressures to take this option.

ACE recommends that:

- A vulnerability assessment be conducted as proposed by CACL;
- An independent panel confirm that a person's request for physician-assisted dying should be accepted; and,
- No provision should be made for substitute consent to physician-assisted dying or for physician-assisted dying through inclusion in advance directives.

We would like to thank you again for the opportunity to provide our submissions in this regard.

SUBMITTED ON BEHALF OF THE ADVOCACY CENTRE FOR THE ELDERLY



Judith A. Wahl
Executive Director
Barrister and Solicitor



Graham Webb
Staff Litigation Lawyer
Barrister and Solicitor