



Canadian Society of Palliative Care Physicians

SUBMISSION TO EXTERNAL PANEL on OPTIONS FOR A LEGISLATIVE RESPONSE TO *Carter v. Canada*

October 2015

This document was created in an effort to best reflect the majority of our members. Recommendations may be different from the personal opinions of individual Society members.

Background

The Canadian Society of Palliative Care Physicians acknowledges the Supreme Court of Canada's ruling to lift sanctions against physician-hastened death. Many requests for physician-hastened death are indications of suffering that could be ameliorated by Palliative Care. If patients were able to receive high quality palliative care, requests for physician-hastened death would be minimized.

Implementing hastened death must be a shared responsibility of Canadian society and the whole medical profession, in partnership with other health care professional colleagues. As a specialty, we see our contribution when patients request hastened death as threefold:

1. To provide and advocate for high quality accessible palliative approach to care
2. To provide clinical service to patients, and education and support to colleagues, in exploring requests to hasten death and in providing palliative care
3. To prioritize and advocate harm reduction
 - a. Potential harm to patients who choose hastening their death because of inadequate support, including palliative care;
 - b. Potential harm to other individuals who may be negatively impacted, including physicians with strong moral opposition to any form of participation;
 - c. Potential harm to the specialty of palliative care, the medical profession and our allied health colleagues.

1. Recommendation to prioritize palliative care

The Canadian Society of Palliative Care Physicians strongly advocates that the most important priority be adequate investment in, and enhancement of, palliative and end of life care services. This investment in palliative and end of life programs must continue prior to and after introducing an option for physician-hastened death, to ensure patients do not choose hastened death due to lack of access to high quality palliative care services.

*Our Canada Health Act states that all Canadians should have universal, comprehensive access to care. This should include access to high quality palliative care. This is currently not the case ^[1]. While we are discussing ways to provide assistance in hastening death, we need to ensure that access to high quality palliative care is prioritized as well. The concrete suggestions in *The Way Forward* ^[2] and the *Canadian Medical Association National Call to Action on Palliative Care* ^[3] should serve as a blueprint to move towards high quality integrated palliative care.*

Concrete actions that can lead to an integrated palliative care approach include:

- *Increased palliative care education in medical schools and residency programs (at a minimum ensure the core competencies as outlined in EFPPEC are taught and evaluated)*
- *CME in palliative care in all specialties*
- *Incentives for physicians to learn and be engaged in thorough discussions regarding goals of care (e.g., billing codes)*
- *Ease of access to specialist palliative care services when needed (e.g., physicians able to call a 24-hour, province-wide number for consultation with a palliative care provider)*

Not only do patients need access to integrated palliative care, they need access to quality information. This includes information about palliative care services, but just as importantly education about death and dying. We need to demystify death, and talk openly about suffering at the end of life and in other difficult situations. We need an education campaign about death, dying, and palliative care that could include:

- *Education in schools about death and the dying process*
- *Media campaigns - TV, print, radio, magazines, social media, etc. to educate the population about palliative care, hastened death, and the very distinct differences*
- *Each province's geographic area (e.g. LHIN in Ontario) should compile a list of all palliative care services available and make accessing them easy for the population*
- *This information could be held centrally*

The main public discourse needs to be about palliative care and the ability to relieve many forms of suffering. Without access to information and services, patients who are suffering may feel as if they do not have choice -- and opt for hastened death because their suffering has been inadequately addressed or they perceive that their families are burdened excessively.

2. Recommendations to support all health care providers and the public

All colleagues providing an interdisciplinary palliative approach to care require protection under the law and within provincial regulations.

Use the language of “hastened death” to replace assisted dying and use accurate terms such as “patient-administered” or “physician-administered” to clarify the exact practice used.

Public and professional education on treatments at the end of life is required to ensure informed decisions.

Palliative care physicians provide medical aid in dying every day. The terms “assisted dying,” “physician-assisted dying,” and “assisted death,” are imprecise and ambiguous, and therefore potentially harmful, as they may be a potential barrier to accessing palliative care services- see section 3 Recommendations to reduce harm to palliative care. The essential concept is that of hastening or accelerating death. If patients believe that assisting in dying is the same as hastening death, then palliative care may become a threatening option for patients opposed to hastened death. More accurate terms include:

- *“patient-administered, physician-hastened death” -- to replace “physician-assisted suicide”*
- *“physician-administered, physician-hastened death” -- to replace “euthanasia”*
- *“physician-hastened death” -- to replace “assisted dying”*
- *“medically prescribed death” could be an option if other professionals were involved*

These recommended terms do not address a troubling and significant area of confusion among both professionals and the public. Many people conflate withdrawal of treatment with a form of hastened death. While the impact of withdrawal may hasten death, it is not through the administration of substances, but rather by allowing the underlying disease process to unfold. Unfortunately, due to the lack of appropriate education, many health care providers consider the use of opioids such to treat pain or dyspnea as death hastening. These subjects should be included in any public or professional death education program.

3. Recommendations to reduce potential harm

The Supreme Court ruled that an absolute prohibition on assisted dying violated section 7 of the Canadian Charter of Rights and Freedoms, which states, “everyone has the right to life, liberty and security of the person.” Autonomy, however, cannot be the sole guiding ethical principle. Careful consideration is required to prevent and/or minimize harm to the individual and to others, including patient family and friends, and society-at-large.

3.1 Recommendation to reduce potential harm overall

If the Parliament of Canada is considering legislation to allow for Physician-Hastened Death, the Canadian Society of Palliative Care Physicians recommends caution by commencing only with physician assisted suicide for eligible persons with a limited prognosis.

The Supreme Court of Canada will lift the injunction against physician-hastened death in February 2016. No country or jurisdiction has implemented a permissive system- physician assisted suicide and/or euthanasia without a limited prognosis- at the start of legalizing physician assisted suicide and euthanasia ^[4]. In other countries and jurisdictions, legislation implementing hastened death focused

initially on cancer patients, and others with more predictable prognoses and outcomes. Only later was the service broadened to include other patients. The Supreme Court of Canada's ruling appears to include a broad spectrum of patients and diagnoses. We expect that a large cohort of Canadians diagnosed with dementia may request hastened death. Rather than implementing a permissive system, we must take time to consider this in a compassionate and thoughtful way. It is not possible to do this safely and wisely by February 2016.

We do have experience to draw on from the US about implementing a more restrictive system- physician assisted suicide with limited prognosis, generally understood to be less than six months. This may be an appropriate place to begin as we continue the conversation about how to implement a more permissive system as outlined in Carter, one that continues to balance autonomy and harm prevention/reduction.

3.2 Recommendations to prevent premature death

Policies must ensure that the desire for hastened death in individuals seeking hastened death is sustained over a period of time that is **proportionate** to the individual's expected prognosis. A standard waiting period is not appropriate for all requests, especially where patients may have years to live- and time to change their minds.

Any professional assessing a patient request to hasten death must have access to appropriate consultation depending on patient need. This may include palliative care, psychiatry, non-malignant pain specialists, gerontologists, spiritual care, addiction counselling etc. alone or in combination. This would ensure all reasonable treatment options have been considered to treat both physical and psychological suffering- especially with the high incidence of depression behind these requests.

Exploring requests to hasten death goes far beyond providing information. Individuals assessing patients requesting assistance in hastening their deaths require special expertise and training.

We should record access to palliative care and include quality measures of palliative care received to ensure decisions are voluntary and not based on inadequate palliative care at the end of life.

Studies have demonstrated that for patients with progressive, life limiting illnesses, the desire for hastened death can change even in the last months of life. ^[5] This means with time patients may accommodate to a new normal. As well, intolerable suffering from a "grievous and irremediable medical condition" can often be contextual and subject to the perspective, experiences, and limitations of the involved clinicians. Physicians inadequately trained to explore and address suffering may not recognize, or be able to provide, realistic options to hastened death.

3.3 Recommendations to reduce potential harm to incompetent patients

The use of the word "adult" in the Carter decision should be understood to mean 18 years.

There are issues specific to pediatrics, geriatrics and those who are not (or will never be) competent:

- *Age of majority is defined differently in each province (age of graduation from pediatric facility, age of driver's license, legal age of alcohol consumption, sexual activity laws)*
- *Some "adults" are followed by pediatric specialists and subspecialists for variable lengths of time beyond age of pediatric facility graduation and age of majority*

- *Concept of emancipated minor equivalent*

Education of the medical community and the general public is needed to ensure that the concepts of consent and capacity are fully understood. All physicians who are asked about physician-hastened death must clearly understand whether the person asking has the capacity to consent to the process.

Implementation of hastened death should not allow for substitute decision makers to request hastened death for their loved one. It is not possible for a surrogate to determine whether the patient is experiencing intolerable and enduring suffering; advance directives are often challenging to specific situations and may reflect a perception of quality that has changed for the patient; and there are not safeguards that could prevent the use of physician-hastened death for reasons other than respect for patient autonomy.

Other consent issues involve individuals who are not competent. Patients who lose their competence require that decisions be made by surrogates, ideally using prior capable wishes or best interests to inform these decisions. Research has shown that in practice it can be very challenging for surrogates to anticipate or recreate the decisions that patients would make for themselves, and even clearly-worded advance directives are difficult to apply in many clinical scenarios.

The language of the Carter decision does not specifically exclude the potential for competent patients to request physician-hastened death by advance directive, raising the possibility that a competent patient could write a directive stating (for example): “If I develop permanent and incurable cognitive impairment and I am no longer able to communicate verbally with my loved ones, or feed myself without assistance, then I would be experiencing intolerable suffering and I direct my caregivers to administer medication to end my life.” Although we understand that many healthy people state that they would not want to live in a state of dependence, we know that people often change their perception about this once they become dependent on others. People with disabilities or dependence rate their quality of life no differently than healthy, able-bodied people. Furthermore, while we acknowledge that some people with advanced neurodegenerative illness appear to be suffering, we have no objective means of confirming that suffering contemporaneously, or (more importantly) determining whether an incapable person’s suffering is “intolerable” to the point that he or she would want their hastened death. Finally, we cannot imagine an effective safeguard or assessment process that would ensure that hastened death is not being used for reasons other than respect for patient autonomy in this scenario.

3.4 Recommendation to reduce harm to health provider conscientious objectors

Create a separate, parallel provincial service to provide information, counselling and referral to willing physicians that can be directly accessed by patient, families, health care providers and institutions.

In consideration of hastened death, physicians’ – and all health care providers’- conscience rights must be respected. Although conscience is often simply portrayed as “for” or “against” hastened death, in practice, it is much more nuanced. In considering participation in hastened death, physicians’ conscience may fall along the spectrum of opposition to any participation, procedural non-participation, non-participation in act, non-interference all the way to participation in the act. ^[6] If a physician is deeply opposed to hastening death, a duty to refer may be seen to imply forced participation procedurally in an

act he or she finds morally abhorrent. An important distinction for many physicians morally opposed to hastening death is the question of who initiates the act. If a well-informed patient initiates the process, physicians may be more comfortable sharing medical information and transferring care if requested. If physicians perceive that they must initiate the process through a duty to refer, many more physicians will experience moral distress. There are ways to facilitate a patient's access to hastened death without compelling individual physicians to formally participate.

Options include:

- a. A separate and parallel system to provide information, counselling and referral that can be directly accessed by patients, families, health care professionals and institutions.*

Services provided could include:

- *Information provision*
 - *End-of-life care: including definitions, explanations of terms, and distinctions between withholding CPR, withdrawal of life-sustaining interventions, palliative sedation therapy, euthanasia, benefits of a palliative approach, death education, etc.*
 - *Information about facilities and services: palliative care units, home palliative care programs, eligibility criteria, and how to begin the application process to palliative care*
 - *Hastened death: rights, eligibility criteria, alternatives, including palliative care or symptom control*
- *Providing or initiating referral to counselling*
 - *To explore the request to hasten death if the patient does not have access to a skilled professional*
 - *May include referral to a willing palliative care professional, spiritual care professional, mental health expert, addictions counselling etc.*
- *Referral to physicians willing to provide hastened death*
 - *Willing physicians would need to register with this service*
 - *Willing physicians would need to be trained and regulated by their provincial Colleges and/or the CMA*
 - *Willing physicians would need to declare which services they were willing to provide: attending or consulting role*

This service could be provincially funded and based, to account for the different healthcare structures in each province. While most palliative care physicians would be willing to inform patients about such a service, a small minority of palliative care physicians would not be willing, for reasons of conscience. A tremendous amount of advertising would be required to ensure that all Canadians know where to find quality information about end of life options. This would require subtlety and finesse, to ensure that Canadians not receive unintended messages that provincial governments are advocating physician-hastened death.

b. Duty to inform rather than duty to refer

Another way to inform, or facilitate access to quality information would be a duty to inform another team member of a patient's request or interest. This could be a robust system to include a way of flagging a patient's request and connecting to another team member willing to provide information or to refer to the separate, parallel system above. The provision of information could also be accomplished with a referral to a patient advocate ⁷. The acceptability of this option to palliative care physicians depends on the permissiveness of the criteria for physician-hastened death. Many more palliative care physicians would be willing to refer to a patient advocate, or have a duty to inform, in a more restrictive system.

c. Team duty rather than individual duty

Rather than expecting all physicians to have the same duty -- whether to refer, inform or not impede access -- we could approach the issue as a team. In a 2015 survey of the members of the Canadian Society of Palliative Care Physicians, 26% of respondents felt that, if legalized, physician assisted suicide and euthanasia should be provided by palliative care service physicians or services ⁸. The possibility exists that within a team, or within a region, a specific separate system could be created to include willing physicians. This possibility may not exist in rural or underserved areas- or in teams where there are not willing physicians. The separate parallel provincial system recommended may need to include a mobile component of service, to respond to areas or teams without registered willing physicians.

In addition to physician responsibilities, healthcare organizations (hospitals and health authorities) should have an obligation to facilitate -- or not impede -- access. If certain healthcare organizations choose not to allow physician-hastened death on their premises for reasons of conscience, they need to establish a transparent mechanism to guide physicians who are asked for such assistance by their patients. This need could be met by a separate service.

3.5 Recommendation to reduce potential harm to palliative care

Physician-hastened death should be a practice distinct from palliative care. Palliative care physicians should not be the gatekeepers in accessing this service. A separate approval, monitoring and oversight body or organization is required.

A recent e-survey by the College of Family Physicians of Canada indicated that many physicians expect palliative care physicians provide physician hastened death ⁹. However, our specialty has worked very hard to ensure that patients understand that our purpose is to be very attentive to enhancing the quality of life and reduce the suffering of persons with a life limiting illness. Without a clear distinction between palliative care and the practice of hastening death, patients' comfort in accessing palliative care could be negatively impacted.

Currently some patients are reluctant to even use opioids appropriately to relieve their pain, because of concerns that it may hasten their death. Some patients have strong objections to hastening death for reasons of conscience. We wish palliative care to remain a safe space where patients understand that we will seek to neither hasten nor prolong death, as per the WHO definition ¹⁰.

Palliative care physicians are deeply committed to working with patients suffering at the end of life and requesting assistance in hastening their death. They are willing to provide consultations in a fashion that

is not simply a requirement to access the service. They are opposed to any system that would set them up to be gatekeepers in hastened death. In a minority of cases, some palliative care physicians may be willing to provide assistance in hastening death as part of a distinct process. Hastened death must not be seen to be equivalent to palliative care.

We are also concerned that patients and physicians might seek out palliative care services with the sole expectation that we will provide physician hastened death. Our members view the practices as being distinct, and many of our members will not perform physician hastened death for reasons of conscience. Thus, patients who seek out palliative care services with the sole expectation of receiving physician hastened death are likely to be referred elsewhere or encounter delays associated with finding willing providers. Patients and referring physicians need to have access to other visible systems of referral so that this scenario is avoided.

3.6 Recommendations to reduce potential harm to families

Policies around hastened death should actively encourage involvement of the patients' close relations. In situations where the patient does not wish to involve others, their rationale should be explored and well documented.

Establish grief and bereavement supports for family, friends and other care providers that are easily accessible for all forms of death.

3.7 Recommendation to reduce potential harm from lethal doses of medications in the home

Pharmacy colleagues must be involved to establish rigorous protocols for the dispensing and disposing of medications used in hastened death, especially if lethal doses of medications are to be prescribed for patient self-administration in the home.

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