

**SUBMISSION TO THE SENATE STANDING COMMITTEE  
ON LEGAL AND CONSTITUTIONAL AFFAIRS**

**FROM CATHERINE FRAZEE, OC, D.LITT., LL.D. (HON.)**

**MONDAY, MAY 9, 2016**

Honourable Committee Members,

I offer the following submission in support of your deliberations on Bill C-14, in my capacity as Professor Emerita in Disability Studies at Ryerson University. My perspective on the issues before you is informed by years of study, writing and teaching in ethics and disability studies, with particular attention to the question of how cultural standards of what constitutes a good and worthy life find their way into social policy and law in ways that can and do marginalize, exclude and ultimately endanger disabled persons. This perspective is also informed by decades of social justice advocacy alongside and on behalf of Canada's disability rights communities, feminist scholars and activists, gay, lesbian and transgendered citizens and other equality-seeking groups, as well as by my term as Chief Commissioner of the Ontario Human Rights Commission from 1989 to 1992. As you are likely aware, for six months last year, along with Dr. Harvey Chochinov and Professor Benoit Pelletier, I was honoured to volunteer in service on the federal External Panel, and to co-author the final report in which we summarized our findings from in-depth meetings with nearly 100 civil society stakeholders and 73 international experts in medicine, law, ethics and other disciplines, as well as from 321 detailed written submissions. Most recently, I have served as an Advisor to the [Vulnerable Persons Standard](#), a comprehensive safeguards framework which I fully endorse, which is now supported by more than 50 national, provincial and community organizations from Canada's medical, disability and faith-based sectors and to which I urge you to give serious attention.

My submission is informed by all of these professional and civic engagements, but it is also deeply infused by my embodied experience as a citizen who lives with a progressively degenerative neuro-muscular condition and who would be considered to be in an advanced state of irreversible decline, but who is privileged with the necessary conditions of respect and support that still permit me to flourish.

**1. THE CRIMINAL CODE MUST BE AMENDED IN ACCORDANCE WITH “A CAREFULLY DESIGNED AND MONITORED SYSTEM OF SAFEGUARDS”.**

I offer my recommendations for Bill C-14 in the spirit of supporting a critically important parliamentary process, recognizing that as parliamentarians you are under tremendous pressure

of time and that if the government of Canada does not enact legislative amendments to the Criminal Code before the Court's June 6 deadline, we will have failed, utterly and inexcusably, to honour the Supreme Court's clear acknowledgment that "the risks associated with physician-assisted death can be limited through a carefully designed and monitored system of safeguards."

The Court was clear in its admonishment that "we should not lightly assume that the regulatory regime will function defectively". Neither, I would submit, should we "lightly assume" that a regulatory regime is unnecessary. The suggestion that parliamentarians might defeat this bill, leaving us with no regulatory regime whatsoever, flies in the face of the Court's assurance that Canada's regime would function as it should. In the most emphatic terms possible, I urge you to recognize, as expressed in the recent [legal opinion of Professor Dianne Pothier](#), that "**it is not a responsible option for the Parliament of Canada to fail to act by June 6, 2016.**"

## **2. THE ELIGIBILITY RESTRICTIONS OF BILL C-14 IN ITS PRESENT FORM MUST BE RETAINED.**

I am deeply concerned about the uproar that has been generated in reaction to the definition of "grievous and irremediable condition" that limits eligibility for medical aid in dying to persons for whom a natural death is reasonably foreseeable. **I urge this Committee to leave section 241.2 (2) intact as it currently stands.**

Bill C-14 is not the answer to all suffering, nor should it be. Interventions to prevent suicide by persons who are not otherwise dying must be a public health imperative for Canada. That is why Bill C-14 draws the line where it must – for persons whose natural death is reasonably foreseeable and who are in an advanced state of irreversible decline in capability.

I urge the members of this committee to recognize both that there are [credible legal opinions](#) affirming the constitutional validity of the approach to eligibility taken in Bill C-14, and further that compelling policy considerations require the critical delineation between medically hastened death and suicide prevention intervention that section 241.2 (2) provides.

As noted by the office of the Surgeon General for National Defense in its [submission to the Joint Parliamentary Committee](#), some persons may request assisted death "where there is otherwise a real possibility of a positive health outcome". Every one of the more than 4000 suicides each year in Canada ends the life of someone who was suffering intolerably. Young men and women in Attawapiskat, Rehtaeh Parsons, Ashley Smith, the 54 Canadian soldiers who took their own lives after serving in Afghanistan – all of these people had enduring and intolerable suffering, but our national responsibility to ease that suffering should never take the form of a hastened death.

Bill C-14 wisely excludes minors, advance directives and otherwise healthy persons who suffer because of a mental illness. Each of these conditions raise complex and difficult questions upon which the Supreme Court gave us no guidance. It would be nothing short of reckless to refuse to study them further.

Limiting the provision of medical assistance in dying to persons who are on a clear trajectory toward death is entirely consistent with the broad sweep of public opinion about who would be eligible to receive an assisted death. Indeed, the co-chair of the Joint Parliamentary Committee, Robert Oliphant, worked to promote this understanding in a number of media interviews conducted following the release of the Joint Committee’s Report. For example, in a [Global News Interview on February 26](#), Mr. Oliphant clarified that that life-ending interventions would be “for people in the final days of their lives”; in a [CTV interview on February 25](#), he similarly framed the issue as providing an option for people “at the end of their days”.

Limiting eligibility for assisted death to persons in “an advanced state of irreversible decline in capability” whose “natural death has become reasonably foreseeable”, is therefore constitutionally sound, consistent with a delicate meshing of competing social policy objectives, and likely to accord with public expectation across the continuum of the assisted dying debate.

### **3. BILL C-14 REQUIRES AMENDMENT IN ACCORDANCE WITH THE UNIQUE REQUIREMENTS FOR VOLUNTARY AND INFORMED CONSENT TO A HASTENED DEATH.**

Let us not lose sight of the fact that medically assisted death has been accepted by the Supreme Court of Canada as an intervention warranted *for persons who suffer intolerably* as a result of a grievous and irremediable medical condition. In order to consent to have one’s life terminated, an autonomous and capable patient must therefore make a choice to die, in preference to any alternative options that might be available to alleviate suffering that has reached an intolerable level. It is suffering that motivates a request to die, and responding to suffering that must shape our regulatory framework for medical assistance in dying.

Suffering, we know from extensive research in psychology and palliative medicine, takes many forms and may be responsive to a wide range of medical, social, psycho-social, technological and other interventions. This broad suite of possibilities to address the particular roots of a person’s suffering must be made known to anyone who requests an assisted death, as an essential requirement of enabling their informed consent. **I would therefore urge this Committee to ensure that the complexities of what constitutes informed consent in the context of assisted death are appropriately reflected in the articulation of physician responsibilities in section 241.2 (3) of Bill C-14.**

As I was able to articulate more fully in the context of [my own submission to the Joint Parliamentary Committee](#), vulnerability is a universal human condition, experienced when persons are stripped by policy or circumstance of our otherwise “firm grip on the social determinants of health.” The Court spoke definitively about the necessity to protect persons who are vulnerable from inducement to pursue an assisted death. This requires from us a more robust formulation of voluntariness than is adequately captured in the simple requirement to screen for “external pressure”. Verifying the non-ambivalent nature of a request for assisted death demands

explicit attention not only to questions of individual coercion, but also to the dynamics of vulnerability. **I would therefore urge this Committee’s attention specifically to section 241.2 (1) (d) of Bill C-14 and recommend amendment to explicitly acknowledge the inducements that arise when access to the social determinants of health is severely compromised or when vulnerability results from such conditions as grief, shame and stigma.**

#### **4. JUDICIAL MECHANISMS OF FORMAL AUTHORIZATION FOR ASSISTED DEATH MUST REMAIN IN PLACE UNTIL A CAREFUL STUDY OF PRIOR REVIEW OPTIONS CAN BE UNDERTAKEN.**

Canada is poised in a mere five weeks to embark upon a social enterprise without precedent in our nation’s history and about which, now 15 months after the Court’s landmark decision, there remains no public consensus and high levels of fear and mistrust on both sides of a vigorous debate. Under such circumstances, the highest standard of diligence is warranted.

Physicians are stewards of human health and well-being. They are not social architects. Those who are willing to administer assisted death, have expressed their willingness to do so in accordance with the law. It is the law, expressed in our Constitution and interpreted by our Supreme Court, that must direct our way forward.

A significant number of Canadian medical, faith and advocacy organizations representing persons with disabilities and seniors recommended in briefs submitted to the Joint Parliamentary Committee that some form of expedited arms-length prior review should be required to authorize Criminal Code exemptions for medically assisted death.

Moreover, in their original submissions at trial, even the plaintiffs in Carter (as reported in paragraph 879 of Justice Smith’s decision) proposed a mechanism whereby physicians would submit medical reports for prior approval by an “expert panel” consisting of an ethicist, a lawyer and a doctor.

If such a process of independent authorization was **not unacceptable** to the Carter plaintiffs in their 2012 pleadings, it is difficult to understand why the Joint Parliamentary Committee would have expressly recommended against this single safeguard. This is especially so, given that in extending its deadline for the coming into force of the Carter decision, the Supreme Court put in place a system of prior review, noting that “*requiring judicial authorization during [the] interim period ensures compliance with the rule of law and provides an effective safeguard against potential risks to vulnerable people.*”

The ideal relationship between physician and patient is one of fidelity and trust. Often, however, these relationships are tainted by asymmetrical relations of power, fundamental differences in how vulnerability is experienced and understood, and predispositions toward the [psychological dynamics of transference and countertransference](#). That the vast majority of Canadian physicians manage these complex relationships with humility, sensitivity and skill is admirable. That [some](#)

do not, accounts at least in part for the vulnerability that many Canadians are known to experience in their encounters with doctors.

The decision whether to administer a hastened death is not a purely clinical decision. It requires a physician's clinical judgment about such matters as a patient's prognosis, capacity and consent, but it also requires discernments of a legal nature concerning the weighing of evidence and the consistency with which terms and thresholds are interpreted.

Because conflicting loyalties may compromise the neutrality with which decisions of legal consequence must be made, and because the written articulation of explicitly reasoned judgment is a required skill set for judges and adjudicators, and because there is at present no Canadian roadmap for a safe and equitable regime of physician-assisted death, I extend my strongest urgings to this Committee, to ***hold in place the current arrangements for judicial authorization of medical assistance in dying, as currently required by order of the Supreme Court, until such time as careful thought and study can be given to whether some form of prior review and authorization is necessary or desirable for Canada in the long term.***

## **5. THE CRITICAL IMPORTANCE OF TRANSPARENCY AND PUBLIC ACCOUNTABILITY MUST BE REFLECTED IN BILL C-14'S PROVISIONS FOR REPORTING AND MONITORING**

As we noted in the Foreword to the External Panel's final report:

Canadian society has a real opportunity to establish itself as a world leader by establishing a robust, modern and innovative oversight system that builds upon the lessons of other jurisdictions currently offering physician-assisted death while setting the standard for those to follow.

Such a system must be built with careful attention to each of three critical realms: sound data collection, effective system monitoring and transparent and accessible reporting practices. Only in this way can we ensure that the practice of medically-hastened death does not compromise the security and well-being of vulnerable persons, and conversely, that safeguards designed to protect vulnerable persons do not impede the rights of Canadians seeking death-hastening alternatives.

With open data comes the opportunity for Canadians to make a clear statement that we believe in transparency and accountability in relation to physician-assisted death.

The collection, monitoring and reporting of data related to medically-hastened death is a critical element of the legislative framework that must be embedded in Bill C-14 amendments. Good monitoring protocols that are equitably designed and scrupulously implemented are a vital foundation to ensure that this new practice does not endanger or disadvantage persons who are vulnerable. It is for this reason that I urge this Committee to ***amend section 241.31(3), so that***

*the development of regulations for data collection, monitoring and reporting is a mandatory rather than discretionary role.* Further, I request that the Committee undertake an amendment to this section that would *give broad guidance about critical information that must be collected, and the terms and purposes for which that information will be made available.* A brief submitted by the Canadian Association for Community Living offers very specific amendments in this regard which I encourage you to consider.

In particular, I would emphasize that upon the coming into force of any new law permitting medically-hastened death, we must immediately begin to collect data to track detailed demographic profiles, geographic factors, diagnostic and prognostic particulars, as well as fundamentally important information about the nature of the suffering that motivates a request and the range of interventions (medical, social, technological, spiritual, emotional, innovative and non-traditional, etc.) that have been offered, considered, pursued, declined or determined to be unavailable. We must have data to track this information for all persons who make a request, whether or not their request is ultimately granted and whether or not it is ultimately administered.

Further, I would underscore the importance of establishing open access to anonymized data for researchers and universities (as distinct from the tightly controlled and therefore currently inaccessible and “secretive” approach to data collection in Québec), along with dedicated funding for both quantitative and qualitative research drawing from this data. Finally, I would urge the Committee to affirm within the provisions of Bill C-14, an explicit commitment to the creation of an oversight body constituted in such a way as to include meaningful representation of vulnerable persons. Again, to quote the External Panel report, “[T]o be credible in the public eye, oversight must be led by trusted individuals, whose work is open, transparent, accountable and rooted in scientific rigor and evidence.”

Amendments such as these will ensure that Bill C-14 satisfies the careful balancing of legislative duties which is the core commitment expressed in the Bill’s preamble.

## CONCLUSION

As you and your colleagues in the House of Commons consider a great many briefs and submissions, I am confident that most understand the need for safeguards to protect against the terrible harm of an unwanted death. Safeguards that speak to formal witnessing, careful evaluation of decisional capacity, independence of physician involvement, screening for ambivalence, a fulsome appreciation of what constitutes informed consent – these are all essential safeguards, and I have faith that you will permit no mischief to weaken these safeguards in Bill C-14. All of the safeguards already in the Bill, and some good amendment proposals that I know have come before you, will satisfy the requirements of the Vulnerable Persons Standard and help to protect against the terrible harm of unwanted death.

But there is another harm about which I urge you to be mindful – the terrible harm of lives given over to despair. When a human being is plunged by some calamitous event of body or

circumstance into disablement, when some accident or catastrophic diagnosis results in immediate or inevitable – and irremediable – disability, despair is never far away. Despair mobilizes with the speed of a heartbeat in that swirl of anger and grief and fear and the loss of all that one had hoped for in life. As we work to invite Canadians to write the last chapter of their story, we must remember that there are larger scripts operating – scripts that are carried in our culture, the stories we tell, the heroes we admire, the dreams that we cherish, the nightmares that we fear. As we debate Bill C-14, let us do so with restraint. Let us do so in a way that does not promote despair as the first response to dementia, or paralysis, or ALS, or a host of other conditions about which today on this very day, people are writing their own stories. Let us remember that those acts of story creation are fragile and the lives that they support are precarious.

Let's not stack the deck with shame and stigma. Instead, we must find neutral ways to talk about such conditions as immobility and incontinence, about the fact that some of us can't swallow and therefore are fed by tube, about what it looks like from the outside when the human mind starts letting go of memory and identity. I urge you, Honourable Senators, in your leadership in this national dialogue, to model respect for life in all of its forms and to embody the principles of our Charter, the principles of respect and equality for all Canadians.

In setting aside the absolute ban on assisted death, the Court expressed its assurance that risks of harm to vulnerable Canadians could be limited by a system of robust safeguards. In good faith, Canada's disability rights, palliative care and faith and conscience-affiliated associations have worked to craft those safeguards that the Court contemplated. In the critical days ahead, I urge you to honour the Court's trust and to set in place the safeguards required to protect vulnerable Canadians from harm.