

Written Submissions of
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to the Standing Committee on Justice and Human Rights

**In view of its study on Bill C-14,
An Act to amend the Criminal Code
and to make related amendments to other Acts
(medical assistance in dying)**

Ottawa
Thursday, May 5, 2016

I was the lead counsel in *Carter* and am able to tell you how the case was framed, what was plead, what evidence was adduced and what was argued.

All of this should inform you whether Bill C-14 will conform to the Constitution and the decision of the Supreme Court of Canada (SCC)

The parts of the Bill that I am most concerned about are:

241.2 (1) A person may receive medical assistance in dying only if they meet all of the following criteria:

...

(c) they have a grievous and irremediable medical condition;

...

Grievous and irremediable medical condition

(2) A person has a grievous and irremediable medical condition if

(a) they have a serious and incurable illness, disease or disability;

(b) they are in an advanced state of irreversible decline in capability;

(c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and

(d) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

This definition of a grievous and irremediable medical condition set out in Bill C-14 is inconsistent with the definition established in *Carter* and as a result Bill C-14 is clearly inconsistent with the Courts' rulings in *Carter*.

Before I elaborate let me state what should be obvious: the SCC's decision in *Carter* set the "floor" and not the "ceiling" of what is constitutionally required to meet the s. 7 rights of all Canadians. This means that while Parliament may extend the rights to physician assisted death ("PAD") beyond what the SCC required, it cannot restrict those rights. I have read that some – even some constitutional lawyers - have suggested that notwithstanding *Carter* that Parliament could justify further restrictions based on s. 1 of the *Charter*. This is simply incorrect. Section 1 was fully argued in the *Carter* case and the Court nonetheless determined what that "floor" of constitutional rights were. In fact it was a "floor" for a defined group of persons: all those with a grievous and irremediable medical condition. Parliament cannot now exclude a whole category of such persons – the physically disabled whose natural death is not reasonably foreseeable - from their *Charter* right to access PAD. This is not to say there is no room for a Parliamentary response to *Carter* or a "dialogue" between the Court and Parliament but that response must be more procedural rather than substantive. By which I mean that Parliament might require certain processes such as having two or more doctors and other safeguards to assess decisional capability for the defined group but it cannot redefine the group in such a way as to deny or

exclude the persons that the SCC expressly included as having the right to PAD.. Hence, there is no room for Parliament to further restrict let alone justify any further restrictions on the s. 7 rights based on s. 1 of the *Charter*.

From the very outset, the *Carter* case was brought in order to make physician-assisted dying available to a “grievously and irremediably ill patient.”¹ We were very deliberate in our choice of words as they were chosen to ensure that the right to PAD not be limited to those whose illness or disease or disability was “terminal” or any euphemism such as where “their natural death has become reasonably foreseeable.”

Canada demanded particulars of this term used in the pleadings² and the plaintiffs responded as follows:

1. A person is “grievously and irremediably ill” when he or she has a serious medical condition that has been diagnosed as such by a medical practitioner and which:
 - a. is without remedy, as determined by reference to treatment options acceptable to the person; and
 - b. causes the person enduring physical, psychological or psychosocial suffering that:
 - i. is intolerable to that person; and
 - ii. cannot be alleviated by any medical treatment acceptable to that person.
2. A “medical condition” means an illness, disease or disability, and includes a disability arising from traumatic injury.³

Notably absent from this definition is any suggestion that the illness, disease or disability be “terminal”.

The defendant Canada specifically noted in argument before the trial judge that the plaintiffs were claiming a constitutionally protected right that is broader than that which was rejected by the Supreme Court of Canada in *Rodriguez*, in the following ways:

- (a) The plaintiffs’ claim includes a right to both assisted suicide and euthanasia.
- (b) The plaintiffs’ claim may not be limited in a meaningful way to physician-assisted suicide or euthanasia because the plaintiffs’ definitions contemplate someone “acting under the general supervision of a medical practitioner” and there is nothing in the plaintiffs’ pleadings that limit who that person might be, or define what “acting under the general supervision of a medical practitioner” means.
- (c) The plaintiffs’ claim challenges not only s. 241(b), but also s. 241(a), the prohibition on counselling suicide. Thus, Canada says, the plaintiffs’ claim would allow physicians to counsel a patient to commit suicide.

¹ Amended Notice of Civil Claim, Part 1, paras. 7-9, 31, 57-60, 64, Part 3, paras. 5-20

² Demand for particulars

³ Plaintiffs Amended Response to Demand for Particulars; TJ Reasons, para. 24

- (d) The plaintiffs' claim relates not to individuals who are terminally ill, but rather to persons who are "grievously and irremediably ill".
- (e) The plaintiffs' claimed right is not limited to individuals who are experiencing intractable suffering; rather, the pleadings require only that the person be suffering "enduring physical, psychological or psychosocial suffering" that is intolerable to that person. Canada says the test is thus entirely subjective and the plaintiffs' pleadings do not require that all reasonable efforts, or even any efforts, have been made to try to relieve the person's suffering.
- (f) The plaintiffs' claim includes individuals who could commit suicide without assistance, and is not limited to persons who are or will become unable to end their own lives without assistance.⁴ [emphasis added]

While the term "terminal" appeared 127 times in the trial judgment and, in particular, is referenced in foreign legislation before the Court (see e.g. paras. 393, 511), the trial judge declined to use that language in her order.

Instead, the trial judge provided the following relevant explanation:

[1386] It is the proper task of Parliament, not the courts, to determine how to rectify legislation that has been found to be unconstitutional. However, in a case such as this, where the unconstitutionality arises from the legislation's application in certain specific circumstances, it is incumbent on the Court to specify what those circumstances are.

[1387] In specifying those circumstances, I begin with the plaintiffs' definition of "physician-assisted dying", "grievously and irremediably ill persons" and "medical condition", but make the following important modifications.

...

[1390] Third, I do not accept that the term "grievously and irremediably ill persons" should incorporate reference to "psychosocial suffering".

[1391] Fourth, the reference to "grievously and irremediably ill persons" should be limited to those who are also in an advanced state of weakening capacities, with no chance of improvement.

[1393] Accordingly, the following declaratory orders will be made:

...

- (b) A declaration that the impugned provisions unjustifiably infringe s. 7 of the *Charter*, and are of no force and effect to the extent that they prohibit physician-assisted suicide or consensual physician-assisted death by a medical practitioner in the context of a physician-patient relationship, where the assistance is provided to a fully-informed, non-ambivalent competent adult person who: (a) is free from coercion and undue influence, is not clinically depressed and who personally (not through a substituted decision-maker) requests physician-assisted death; and

⁴ TJ Reasons, para. 30

- (b) has been diagnosed by a medical practitioner as having a serious illness, disease or disability (including disability arising from traumatic injury), is in a state of advanced weakening capacities with no chance of improvement, has an illness that is without remedy as determined by reference to treatment options acceptable to the person, and has an illness causing enduring physical or psychological suffering that is intolerable to that person and cannot be alleviated by any medical treatment acceptable to that person.⁵ [emphasis added]

The relief granted by the Supreme Court of Canada was even broader than that granted by the trial judge. The Court held:

[4] We conclude that the prohibition on physician-assisted dying is void insofar as it deprives a competent adult of such assistance where (1) the person affected clearly consents to the termination of life; and (2) the person has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. We therefore allow the appeal. [emphasis added]

And again:

[127] The appropriate remedy is therefore a declaration that s. 241(b) and s. 14 of the *Criminal Code* are void insofar as they prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life; and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. “Irremediable”, it should be added, does not require the patient to undertake treatments that are not acceptable to the individual. The scope of this declaration is intended to respond to the factual circumstances in this case. We make no pronouncement on other situations where physician-assisted dying may be sought. [emphasis added]

Thus the Court made no reference to the patient being “terminal” or to their natural death being “reasonably foreseeable”. Nor did the Court include the language of being “in an advanced state of weakening capacities” (as the trial judge did), with no chance of improvement let alone “in an advanced state of irreversible decline in capability.” While the Court, in paragraph 127, explained that the declaration was intended to respond to the factual circumstances of the case, it must be noted that the factual circumstances in this case were not limited to one woman dying of ALS. In fact we framed our case to ensure that, unlike the *Rodriguez* case, it would not be about one person but brought to advance the rights of all Canadians and it was for that reason that one of the plaintiffs was the British Columbia Civil Liberties Association which was granted “public interest standing” for that very purpose. And in light of that we provided the court with the heart wrenching stories of persons from all across Canada and indeed beyond since suffering knows no national boundaries.

As the Supreme Court of Canada itself noted:

⁵ TJ Reasons, para. 1393

Other witnesses also described the “horrible” choice faced by a person suffering from a grievous and irremediable illness [spinal stenosis, Huntington’s, Parkinson’s, MS, locked-in syndrome]. The stories in the affidavits vary in their details: some witnesses described the progression of degenerative illnesses like motor neuron diseases or Huntington’s disease, while others described the agony of treatment and the fear of a gruesome death from advanced-stage cancer. Yet running through the evidence of all the witnesses is a constant theme - that they suffer from the knowledge that they lack the ability to bring a peaceful end to their lives at a time and in a manner of their own choosing.⁶

The Court was presented with evidence from physicians, individuals and the loved ones of individuals with the following grievous and irremediable conditions where natural death was not necessarily reasonably foreseeable. One such illness has been called “locked-in syndrome”. This is caused by a stroke to the so-called “ventral pons”. A stroke in this region leads to profound neurologic dysfunction characterized by tetraplegia, that is, the inability to move the arms, legs and head. The patient is unable to chew, swallow or communicate verbally. The only motor function that is maintained is the ability to blink as well as the ability to move the eyes, typically only in the vertical plane. Cognition is unaffected. As the name of this syndrome implies, a normal mind is essentially locked in an immobile body. The significant reduction of the quality of life in this state is self evident. From a physical standpoint, patients are unable to interact with their environment. While communication can take place via blinking, et cetera, communication is slow, fragmented and difficult to carry out. With adequate medical and nursing care, patients can survive in this state for decades. Significant recovery is rare.⁷

Allow me to share a bit of the exchange I had with the Court in the *Carter* case which makes very clear what we meant by the phrase “irremediable”.

MADAM JUSTICE ABELLA: One of the qualities that you said we should look at in permitting assisted dying is irremediable medical conditions.

MR. ARVAY, Q.C.: Yes.

MADAM JUSTICE ABELLA: How is that consistent with your argument that an individual has the right to decide the quality of his or her life based on a dignity interest?

MR. ARVAY, Q.C.: Because our argument is founded on what Professor Battin sort of described as both principles of autonomy and the value of mercy. Because we are seeking to constitutionalize or to strike down the law that criminalizes assistance in suicide, we don’t rely on autonomy alone, we rely on autonomy and suffering.

MADAM JUSTICE ABELLA: But that can exist whether or not the medical condition is irremediable. I’m just asking why you think that has to be a condition that you impose in the decision to strike down when somebody wants the assistance of a doctor. Why can it not be a medical condition period? What is there about the ability of somebody to choose that should be restricted by the longevity or the fatality, the expected fatality of the illness?

⁶ SCC Reasons, para. 14

⁷ Meckling, para. 23, 25-26, 28-31; Nicklinson #1, Exhibit B, C, F

MR. ARVAY, Q.C.: Well, first of all, we do not limit our claim to the terminally ill. People like Tony Nicklinson who had locked-in syndrome, which means he was going to live for 20 years.

MADAM JUSTICE ABELLA: So what do you mean by –

MR. ARVAY, Q.C.: So we had people like that in mind as to say that we are not limiting our case to the terminally ill, but we are limiting our case to people whose condition is irremediable or incurable, if you want to use that language, because assisted dying should only be allowed in the most serious cases and not just because somebody wants to, it's because their condition is not going to get any better.

MADAM JUSTICE ABELLA: Thank you.

MR. ARVAY, Q.C.: Okay.

MADAM JUSTICE ABELLA: That's what I wanted your clarification on.

MR. ARVAY, Q.C.: Yes. Thank you.

And here is an excerpt from the evidence of Tony Nicklinson our affiant who suffered a massive stroke at the prime of his life and was left with locked-in syndrome since the only muscle in his body that he could move were his eyelids and he managed to “type” out his affidavit one blink at a time:

2. Where to start? I am a 56 year old man who suffered a catastrophic stroke in June 2005 whilst on a business trip to Athens, Greece. It left me paralyzed below the neck and unable to speak. I need help in almost every of my life. I cannot scratch if I itch, I cannot pick my nose if it is blocked and I can only eat if I am fed like a baby – only I won't grow out of it, unlike the baby. I have no privacy or dignity left. I am washed, dressed and put to bed by carers who are, after all, still strangers. You try defecating to order whilst suspended in a sling over a commode and see how you get on.

3. I am fed up with my life and don't want to spend the next 20 years or so like this....

5. I'm not depressed so do not need counseling. I have had almost five years to think about my future and it does not look good. I have locked-in syndrome and I can expect no cure or improvement in my condition as my muscles and joints seize up through lack of use. Indeed, I can expect to dribble my way into old age. If I am lucky I will acquire a life-threatening illness such as cancer so that I can refuse treatment and say no to those who would keep me alive against my will. Unfortunately, I don't smoke or drink any more - have you ever tasted thickened beer? No? Then perhaps you should - so tobacco or alcohol induced diseases are out and since I rarely go outside the likelihood of me catching a fatal disease is low.

6. Letting nature take its course can, I admit, take a long time or not work at all but what do I have since do-gooders - those people who want assisted suicide to remain illegal – took away my right to decide my own fate, a right which, incidentally, they have. Why deny me and others who need help? Is it because I'm disabled?

7. Perhaps I somehow can't be trusted to make the “right” decision? Have I suddenly lost my intellectual ability? If that was really a criterion, then probably half the

country would be ruled out. Or is it something else? I would like to see a do-gooder explain that to me. The flaw in their argument is the assumption that we all want to live whatever the cost in terms of quality of life when this is clearly not the case. I want to make that choice for myself. What prevents me is the fact that I am too disabled to take my own life and unlike an able bodied person I need help to die.

8. By all means protect the vulnerable (by vulnerable I mean those who cannot make decisions for themselves,) just don't include me. I am not vulnerable. I don't need help or protection from death or those who would help me – if the legal consequences were not so huge - life imprisonment.

9. I am asking for my right to choose when and how to die to be respected. I know that many people feel that they will have failed if someone like me takes his own life and that life is sacred at all costs. I do not agree with that view. Surely the right and decent thing to do would be to empower people so that they can make the choice for themselves. Also, why should I be denied a right – the right to die of my own choosing when able bodied people have that right and only my disability prevents me from exercising that right. In the interests of equality surely the state should help to equalise the position between someone like me and some one who is not disabled?

Mr. Nicklinson started his own action in the UK and lost. Shortly afterwards he chose to starve himself to death. Anyone who knows about the process of self-starvation will know that it is a most cruel way to die. Yet that is exactly what this Bill if enacted will force all those persons who the Minister claims are persons “with a major physical disability who is otherwise in good health,” (Hansard April 22, 2016) and who she says should not be allowed to die “prematurely”.

In fact it is very clear to me that the primary purpose and certainly the effect of the reasonable foreseeability clause (other than to deal with the mentally disabled which can be addressed with more carefully drafted provisions) is to deny most physically disabled persons - whether disabled from birth or from some trauma or accident mid-life or from a stroke later in life, the choice of a PAD. This of course was the very position advanced by the disability organizations who opposed our case and whose main spokespersons - whether it was the expert witness Professor Catherine Frazee or their counsel David Baker – both of whom I expect you have or will hear from.. So let me end by telling the Committee something I suspect no one has or will tell you.

It wasn't long after we started the action to challenge the laws that I realized that my main opposition was going to be from some of the disabled rights organizations. As a physically disabled man I was very sensitive to opposing the position of organizations that I respected and of whom I might be described as a “member”. So I thought long and hard about this and I did extensive research.

This is their argument in a nutshell and it is based on what has been called the “social model of disability theory.” That someone like Stephen Fletcher or Tony Nicklinson or Elayne Shapray or even me are not really “disabled”. Rather we are simply “impaired” by our injuries or illnesses. We are not “disabled” because it is only “ablest society” that sees us as “disabled”; we are “disabled” not only by a society that allows buildings to be built with stairs, but by ablest society's conception of what it means to live a dignified life. Indeed many able bodied persons might think that one is: “better off dead” than to live a life in which one needs machines to move

about or to have 24 hour caregivers to attend to one's most personal and intimate needs. The disabled rights organizations have rejected that conception of what is or is not a "dignified life". And let there be no mistake: I entirely agree with them that there is no one conception of the dignified life. I agree that for most physically disabled persons needing machines to move or even breathe and caregivers 24/7 is just what one needs to get on with their life and most of us do so without losing our dignity. But what I consider most offensive is the very patronizing view that what may be tolerable and dignified for some physically disabled person must be tolerable and dignified for all. I reject the idea that all or even some physically disabled persons will somehow be consciously or unconsciously duped or cajoled by their family or even their doctor into believing that they would be "better off dead." This view denies the physically disabled their agency and autonomy; it treats us not only as some homogenous group, but as if we are all children; in a word it is infantilizing of the physically disabled. The trial judge heard much evidence from experts on the "social disability" theory including from one of its leading proponents who has finally concluded that it should be abandoned insofar as it is invoked to prevent the physically disabled from exercising the same rights as the able bodied to seek physician assistance in death. He said:

Perhaps social model ideology enables some to disengage from troubling questions about bodies and mortality.

In other words, while it is undoubtedly the case that there are societal reasons that are the cause of discrimination against the disabled, for all of us it is our medical condition that is very real and for some of us (even if a very small minority) that medical condition causes intolerable suffering and relief from that suffering cannot be denied just because most can otherwise tolerate it or adapt to it.

In sum, as one of our experts opined, and the trial judge, this ideology advanced by some of the disabled organizations to deny the physically disabled the right to PAD "feeds rather than starves discriminatory attitudes." And it is for that very reason that not all disabled organizations adhere to that view. Indeed one of the groups that intervened in support of our claim was the Ad Hoc Coalition of People With Disabilities Who are Supportive of Physician-Assisted Dying, represented by Angus Gunn who I understand might be appearing or has appeared before you.

Somewhat relatedly are the views recently expressed by Professor Pothier who I understand you have or will hear from. She defends the clauses in question on this basis:

... the proposed subsections 241.2(2)(b) and (d) in the legislation are important in designing safeguards against error and abuse. If there is no state of irreversible decline in capability, and death by natural causes is not reasonably foreseeable, the consequences of potential error are substantially magnified. Without the limitations of subsections (b) and (d), physician-assisted death will remove, over a lengthy period, the possibility of a person changing their mind. The odds of a transitory suicidal wish becoming reality increase. There are greater risks that the notion of a disabled life not being worth living will creep into assessments. Thus vulnerability concerns are substantially magnified if

physician-assisted death is not limited as in subsections (b) and (d), and thus would weigh more heavily in the balance.⁸

There is nothing new in this argument. The idea that someone might change their mind but for the availability of PAD or that their suffering is transitory was front and centre both before the trial judge and the SCC. The trial judge said this:

[755] I will briefly digress in order to comment on the term “wrongful death” that Canada employs throughout its submissions.

[756] Canada’s use of the term “wrongful death” is somewhat troubling....

[757] Canada rolls into the “wrongful death” concept the notion that any death which is chosen is wrongful because the individual who made that choice may regret it later (if regret is possible after death). In my view that goes much too far. People choose to forego life-sustaining treatment, and choose to end treatment in circumstances where the cessation of treatment will hasten their deaths. People choose to embark on risky activities. Many decisions in life have foreseeable, adverse consequences, including the consequence of death. The argument employs reasoning based on hypotheticals such as “if they were able, they might regret that decision” to characterize the results of those decisions as “wrongful”. I find that line of reasoning unusual and unpersuasive.

As to the claim that the suffering of some physically disabled persons might be transitional, there is no question that this point was amply argued before the SCC. This exchange with Justice Abella and David Baker is simply one example.

MR. BAKER: ... The questions must be asked whether any exception could possibly be intended to cover persons who are suffering psychologically because they cannot accept losing physical independence, because they do not wish to impose the burden of their deterioration on others, because they find it intolerable to have someone assist them with toileting.

MADAM JUSTICE ABELLA: Are you denying that there’s a dignity component in all of this?

MR. BAKER: I’m denying that there should be a public program of assisted dying for people in circumstances such as these were those concerns - **the suffering can very well be transitional, transitory or situational**. My clients’ position is that the criteria far too broad in the trial judge’s decision, broader than in any other jurisdiction in the world, and yet across the world the average annual rates of dying are growing between 14 and 64 percent a year with no end in sight.

MADAM CHIEF JUSTICE: I think at this point I’m going to have to ask you to wrap up and sit down, please.

Both Professor Pothier and David Baker’s concerns about suffering being transitional or situational can be met by requiring more safeguards in the assessment process, not a *per se* disqualification because one is physically disabled and “otherwise healthy”. . And to reiterate what I mentioned at the start section 1 provides Parliament with no justification for these

⁸ <http://policyoptions.irpp.org/2016/04/29/doctor-assisted-death-bill-falls-well-within-top-courts-ruling/>

provisions of the Bill. In *Carter* the SCC struck down the blanket prohibition - which this Bill still imposes on all physically disabled persons whose natural death is not reasonably foreseeable – but said that Parliament can protect these and all other potentially vulnerable persons not by their exclusion from PAD but by practices and laws that ensure that those seeking PAD are properly assessed for their decisional capacity: *Carter* SCC e.g.at paras 114-117.**Requiring the physically disabled to suffer intolerably until their death is foreseeable has nothing to do with the assessment process.**

Here is the bottom line: the trial judge heard all of the arguments advanced by the disabled rights organizations (and every other party that opposed PAD) as did the SCC. And they were soundly rejected. And yet what this government is seeking to do is to give to those groups the very thing that the SCC rejected and denied them. That would indeed be a very perverse outcome of the *Carter* decision.

I conclude by telling you that it is my professional opinion that Bill C-14 is fatally defective by the inclusion of these clauses. I base this opinion not only on the fact that I was the lead counsel in *Carter* but also on my having what is arguably more experience litigating the *Charter* from its inception 34 years ago than any lawyer in private practice in Canada.. If not removed I can assure you that they will be struck down by the courts. But I implore you not to leave to the courts what ought to be the job of Parliament in the first place: to enact legislation that upholds our *Charter* rights and values without the need for further time-consuming, protracted and expensive litigation pending which those Canadians left out of Bill C-14 will needlessly and intolerably suffer.

ALL OF WHICH IS RESPECTFULLY SUBMITTED.



Joseph J. Arvay, Q.C.