



## Memorandum

**To:** The Members of the Special Joint Committee on Physician-Assisted Dying, Parliament of Canada  
**Re:** Response to comments made during the Committee Hearing of January 28, 2016  
**Date:** February 2, 2016  
**From:** Trudo Lemmens, Professor and Scholl Chair in Health Law and Policy

### Introduction

With this memorandum, I want to respond to comments made during the Committee Hearing of January 28<sup>th</sup>, and also alert the Committee to some relevant new evidence that has come to light yesterday that confirms the need for a prior review system.

I first want to make a comment in relation to the more general questions the Committee asked about what the *Carter* decision requires Parliament to do. Professor Downie and the Provincial Territorial Advisory Group [PTAG] interpret *Carter* very broadly. They recommend transporting the vague 'parameters' of *Carter* directly into the legislation without need for clear definitions or additional safeguards. They even suggest that precise definitions and prior review are not in line with *Carter*. This Committee should in my opinion be guided by the realization that, as the Supreme Court strongly emphasizes, *Carter* deals with a narrow, exceptional situation, which the Court felt should not have been captured by what is currently an absolute prohibition. The Supreme Court did not enact clear guidance about how to fix this, since it explicitly left it up to Parliament to develop a "very strict regulatory regime with rigorous monitoring to prevent abuse." This system, it stated explicitly, could be more precise and offer more safeguards than the Belgian regime and thus avoid the type of problems that have come to light with respect to a PTAG-style regulation. The general parameters of *Carter* should guide the legislative process, but they are parameters, not detailed legislative rules. To transpose these without any further specification would amount, to quote Justices McLachlin (as she then was) and Iacobucci, to "slavish conformity [that] would belie the mutual respect that underpins the relationship between the courts and legislature that is so essential to our constitutional democracy."<sup>1</sup>

The emphasis in the *Carter* decision on the narrow circumstances of the case (a person 'like Ms. Taylor'), the explicit statement that "euthanasia for minors or persons with psychiatric disorders or minor conditions" does not fall within the parameters of the case, and that it is up to Parliament to develop a rigorous system indicate that *Carter* is much more narrow than Professor Downie and some other esteemed colleagues suggest. Moreover, if the Supreme Court had felt that the type of competency assessment the PTAG relies on would be sufficient, it would not have suspended the declaration of invalidity and would not have renewed this suspension while making Quebec—which has a much more narrow PAD system—exempt from the suspension of invalidity.

It is worth noting here that the trial judgment contains a much more precise definition and stricter conditions for who should have access to PAD. The Supreme Court never rejected this narrow definition and never criticized it. It simply left it open to Parliament to come up with the more precise terms and conditions for access to PAD.

I also want to respond to some specific comments. I will first respond to the argument directly in relation to the evidence I presented. I will then say something about specific *Charter*-compliance arguments made by Professor Downie, which I disagree with. I have discussed my arguments with other legal scholars, including constitutional experts, having presented a forthcoming paper laying this out in more detail at our Faculty of Law, and found substantial agreement with my interpretation of *Carter*.

### **1. The relevance and strength of the Belgian evidence and new evidence:**

Professor Downie stated: “what you have to rely on ... in relation to the Belgian data, is the evidence that was tested in court and the empirical evidence from the actual researchers. In *Carter* and at the Supreme Court level it was presented so it was updated.” I disagree. The Committee should look at relevant new evidence, and should also take the liberty to consider the evidence earlier presented in court *for its own purpose* of designing the best regulatory regime. Much of the evidence I presented to the Committee was not discussed at the trial level. In my report to the Committee, I relied specifically on a peer-reviewed study of euthanasia and mental health published in 2015 in the professional medical literature and ongoing research on Dutch euthanasia cases by psychiatrist-bioethicist Dr. Scott Kim. This evidence shows serious problems with relying on competency assessment, determination of access by individual physicians on the basis of vague criteria, and after the fact reporting. These three tools are the main mechanisms for protecting the vulnerable in the PTAG proposal. The Committee should take these reports very seriously, since it reveals how a flexible, open-ended regime as proposed by the PTAG puts people with mental illness at risk.

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The Flemish National Radio and Television (VRT) just reported on February 2, 2016 in detail on the case of a woman in her 30s who was diagnosed with autism merely two months prior to the performance of euthanasia, a diagnosis that then was used to support the claim of her suffering from an irremediable disease. The documentary confirms the problems identified in the reports I already discussed with the committee: over-reliance on individual physicians (and doctor shopping); overly broad criteria; easy diagnosis of ‘irremediable’ conditions, failure of independent assessment by specialist, failure of Federal Control and Evaluation Commission to find any problem—the criteria of the law were respected). I recommend reading some of the details of this new troubling report in reference. In response to this case report, a leading psychiatrist commented: “The time following a euthanasia request must, according to the law, be one month. But in fact a year is in such case even too short.” “The law aims primarily at people in terminal situations.... This is about people who suffer psychologically. **Is a prior evaluation not much more reasonable, whereby a commission discusses a case beforehand?**”<sup>2</sup> This is what it is all about. No one wants to see similar cases happening in Canada. Yet this case would be possible under the PTAG recommended model.

Some—but not all—of the controversial cases I discussed were indeed presented by an expert witness before the Supreme Court. But I provided more evidence on some of these, including information from interviews with physicians involved. The Supreme Court ruled these cases outside of the parameters of *Carter*. In other words: the Court felt it did not have to consider the evidence, since it counted on Parliament to design a system that would be more rigorous and less open-ended than the Belgian system and that *would not allow PAD in such cases*. The PTAG now recommends providing access to PAD on the basis of very open-ended criteria, including for mental health conditions. The evidence thus becomes very important for the Committee to consider.

Finally, in the trial judgment, Justice Smith acknowledges, with quotations from expert witnesses for the plaintiffs, that there may be problems with the Belgian system and that it was difficult to draw a clear conclusion.<sup>3</sup> New evidence confirms the problems admitted prudently at the trial level.

## **2. Specific Comments: Definitions and Charter Compliance:**

**2.1. Definition of grievous and irremediable condition.** The Belgian evidence confirms the importance of a precise definition. The Trial Judge also worked with a more narrow and precise definition. The Supreme Court emphasized repeatedly that its decision was focusing on people in the situation of Ms. Taylor, that it was not saying anything about PAD for psychiatric patients, minors, or for minor conditions. This indicates that the Court was ruling with the narrow definition and precise criteria of trial judge Justice Smith in mind and did not intend to bind the legislature with its overly broad criteria.

Limiting access to instances of “**terminal illness**” has a strong moral basis for access, since it reflects a reasonable balance between the risk of prematurely ending a person’s life, and the benefit of offering compassionate care at the end of life. It is not too vague and can be defined more precisely. This would not violate *Carter*.

## **2.2. PAD and Mental Illness**

Professor Downie argues that excluding mental health as a basis for PAD would violate the *Charter*. I disagree. Obviously, competent adult persons should not be excluded from accessing PAD for the same conditions and under the same circumstances as others because they suffer from a mental illness. But defining ‘grievous and irremediable’ narrowly is not unconstitutional simply because the definition does not include or capture psychiatric diseases. A narrow definition will in fact ensure that there is no confusion about PAD in the context of mental health: people with mental health conditions could have access to PAD when they are competent, but only in situations that are covered by the law. The reference to psychological suffering in *Carter* is with respect to the suffering that accompanies being affected by a grievous and irremediable condition.

As mentioned before, the Supreme Court explicitly stated that Professor Montero’s case-based evidence about the risks of legalizing PAD was irrelevant, because euthanasia for “persons... with psychiatric disorders” was outside the parameters of the case. If the SC had in mind that its broad criteria inevitably included psychiatric diseases, it would *not* have stated this since it

would bring the evidence relevant and within the parameters of its ruling. The complexity of the interaction between mental illness and competency, the difficulty of determining when mental illness is ‘irremediable’ and treatment-resistant, and the potential very negative impact of offering life-ending PAD as a ‘treatment option’ on the clinical care of people with mental illness justify a more protective approach.

Psychiatric diseases can be kept outside the definition of grievous and irremediable, a definition which should focus on ‘*Carter*-like cases’. But it is also perfectly compatible with the *Charter* and in my view even required under equality law to provide additional protection and scrutiny when that is needed to protect those who are more vulnerable (substantive equality approach).

### **2.3. Age Restrictions**

Professor Downie stated: “To exclude individuals on the basis of a specific age flies in the face of established health law, policy, practice, and the charter.” I disagree. It is true that the law recognizes mature minors’ significant decision-making powers in the context of health care, including with respect to treatment refusal. Yet, setting an age limit or differentiating on the basis of age is frequently done in the context of health law and is not a violation of the *Charter*. The *Assisted Human Reproduction Act* prohibits gamete donation under the age of 16, and surrogacy under the age of 21. These restrictions have not been challenged in court.

*AC v Manitoba*<sup>4</sup> neither stands for the claim that age differentiation is a violation of the *Charter*, nor that mature minors have to be treated as adults. Rather, the case explicitly confirms that when it comes to minors, the best interest of the child is key, which takes account of the growing ability of young adolescents to make autonomous decisions. The complexity of the decisions and the risks involved are key components of a best interest of the child analysis.

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In other words: when it comes to minors, additional safeguards and age differentiation are the norm in relation to very complex and risky decisions. There is arguably no other decision that is more ‘life-changing’ than a request to have one’s life terminated. The legislature should explain the rationale for age restrictions or differentiation. It would clearly be compatible with the *Charter* to impose additional protective measures or additional judicial review for access for mature minors and to focus the legislation in principle on adults.

### **2.4. Binding Advanced Directives**

Professor Downie defends the notion of binding advanced directives, specifically in the context of dementia. If one follows her argument, a person who experiences a diagnosis of onset of dementia as creating intolerable suffering can specify in an advanced directive that her life be ended in circumstances she identifies. “This approach prevents [among others] the tragic case of someone having met all the criteria, but being denied medically assisted death because they became incompetent just before it could be provided.”

When you couple this proposal for binding advanced directives with the PTAG’s subjective and open-ended nature of the definitions of “intolerable suffering” and a “grievous and irremediable” condition, this could lead to the following situation: A person specifies at a very early stage of Alzheimer in an advanced directive that they want to be killed with PAD when

they no longer recognize their family members. At that stage, people can still be functional, find pleasure in life, engage meaningfully with their environment, and continue to live for a long period of time. I have trouble understanding how it can be morally defended that physicians can or even should actively end people's lives in those circumstances on the basis of an advanced directive and a quite hollow concept of autonomy (an autonomy fixed on the basis of how the person used to be). It seems to me impossible to deny that accepting active life-ending actions in those circumstances is a direct affront to the inherent dignity of human beings, regardless of their intellectual capacities. Active life-ending actions in those circumstances is further traumatizing for family and health care providers. It should not be allowed. Note that this does not mean that the individual in such a situation would not receive medical assistance and could not be kept comfortable and supported with all available means already at our disposal. The unfortunate nature of an incompetent person not being able to choose the precise timing and circumstances of her death must be weighed with against the significant moral problems I mentioned here.

## **2.5. Prior Review and *Morgentaler***

Professor Downie objects to prior review systems and suggests that the proposal by David Baker and Gilbert Sharpe would not be in line with *Morgentaler*. David Baker has explained how flexible and fast a prior review panel can and should act (taking into consideration that in some specific circumstances obligatory waiting periods can actually prevent premature life-ending actions). No one proposes undue delays when decisions have to be made fast.

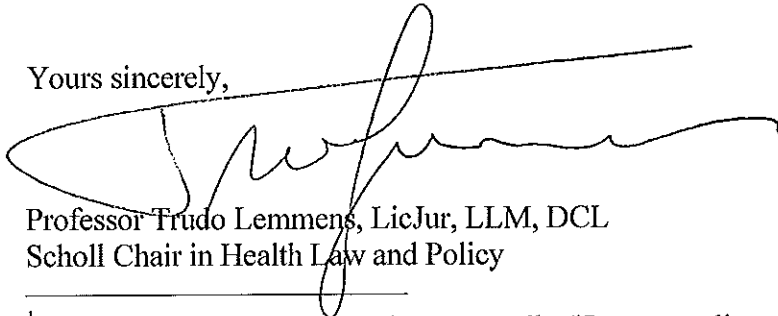
A prior review system for PAD would be *Charter* compliant. The review structure for PAD has a very different purpose and a different impact than the review system held unconstitutional in *Morgentaler*. Decisions related to abortion are not the same as decisions at the end of life. First, in the abortion context, the issue of equality of women is key. Second, in the abortion context, review panels were set up because of "the state interest in the protection of the foetus" and this 'other' interest imposes arguably a burden on a pregnant woman in the context of unwanted pregnancy. In the end of life context, the review aims at protecting the person him or herself. Third, competency issues are in the context of PAD clearly a key concern; not so in the context of abortion. Fourth, in the abortion context, fast intervention is generally important because of the risks and potential trauma of continued unwanted pregnancy and late-term abortions. In PAD, continued suffering can indeed also be traumatizing, but this must be weighed against the risks of prematurely ending a person's existence and the fact that in some cases, if waiting periods are warranted, delay may mean withdrawal of request for PAD because the issues that spurred the request have been addressed.

If the Supreme Court would be faced with a constitutional challenge in relation to a prior review system, I am confident that the Court would distinguish prior review panels in the abortion context from prior review panels in PAD. *Morgentaler* is not a relevant precedent.

For all these reasons, I am fully supportive of the approach proposed by David Baker and Gilbert Sharpe, as well as others, who argue for narrowly defined access to PAD, and for a stringent administrative review system prior to allowing PAD, coupled with a strong reporting system and regulatory monitoring.

I thank you for considering these responses to the issues raised. It has been an honour to be able to participate in this very important debate that affects all Canadians.

Yours sincerely,



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<sup>1</sup> McLachlin & Iacobucci JJ in *R. v. Mills*: "Just as parliament must respect the court's rulings, so the court must respect Parliament's determination that a judicial scheme can be improved. To insist on slavish conformity would belie the mutual respect that underpins the relationship between the courts and legislature that is so essential to our constitutional democracy." At par. 55.

<sup>2</sup> Quotes (my translation and my emphasis) from "Zussen getuigen over amateuristische euthanasia: Baxter viel op Tines gezicht" De Morgen (2 February 2016) online at <http://www.demorgen.be/binnenland/zussen-getuigen-over-amateuristische-euthanasie-baxter-viel-op-tines-gezicht-b92f407b/>. The case was reported in detail in a documentary with interviews on the Flemish National Radio and Television programme Ter Zake (a political-social issues show akin to The Agenda, which combines panel discussions with short documentaries). It interviewed two sisters of a young woman who was euthanized in 2010, four months after requesting euthanasia. She had been in psychiatric treatment 15 year earlier, but had been able to build a stable life since. Yet, following a break-up, she had a serious mental health crisis, and was in treatment with a psychiatrist for 8 months. Two months before her life was ended, the psychiatrist diagnosed her with autism, and concluded that she had an irremediable illness, and that her psychological suffering was unbearable. She was euthanized in the presence of her family, in problematic circumstances. When her family members inquired with her family physician why he had confirmed the psychiatrist's assessment of the euthanasia request, and whether he was supportive of this, he admitted that he was not in agreement, but that he had no choice. He states (recorded): "I think Tine shopped with too many doctors. I am also a bit angry at the doctor who gave that injection. The way in which he was quickly happy to do certain things. Perhaps there is need for a debate. And a break on people who like to do this technically" The third physician who confirmed the assessment was not a psychiatrist (since it was not a case of terminal illness, a third assessment was required). The case was not reported within the prescribed period of time, but when it was reported, the Federal Control and Evaluation Committee had no problem with it.

<sup>3</sup> For example, Justice Smith states: "[672] With respect to Belgium, it is difficult to reach any firm conclusion. In cross-examination, Professor Deliens acknowledged that patients who do not have a psychiatric disorder but who have some level of depression might be vulnerable to being euthanized...". The evidence produced at the trial level was clearly not fully up to date: at par. 548, Justice Smith cites a study that mentions that requests for "patients with a psychiatric disorder were never granted euthanasia." This is clearly not (or no longer) the case.

<sup>4</sup> *A.C. v. Manitoba (Director of Child and Welfare Services)* [2009] SCC 30