UNIVERSITY OF TORONTO
FACULTY OF LAW

Trudo Lemmens, LicJur, LLM (bioethics), DCL
Professor and Scholl Chair in Health Law and Policy
Faculty of Law, University of Toronto
Jackman Law Building
78 Queen's Park
Toronto, ON, Canada M5S 2C5
Trudo.Lemmens@utoronto.ca

Submission to the Joint Parliamentary Committee on Medical Assistance in Dying: Corroborating Evidence in Response to Questions Committee Hearing Advance Requests for MAID

Trudo Lemmens (LicJur, LLM(*bioethics*), DCL)
Professor and Scholl Chair in Health Law and Policy
Faculty of Law, University of Toronto
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This memorandum provides evidence and more detailed arguments to corroborate my testimony at the May 9 hearings of the Joint Parliamentary Committee on Medical Assistance in Dying. This responds to questions about the evidence in support of my key points about the practice of advance requests for MAID in Belgium and the Netherlands, and the reasonableness of the argument that legalizing advance requests for MAID would violate constitutional and human rights norms.

1) Evidence and documentation of Dutch practice of euthanasia/MAID of persons with dementia

My testimony largely—but not exclusively—built on the Council of Canadian Academies [CCA] Expert Panel Committee Report on Advance Requests for MAID,[1] which was mentioned in my testimony, and which was commissioned by the government to provide a detailed a review of relevant evidence. The committee members have this report at their disposal. I contributed extensively to this report as an expert member of the CCA Expert Panel. The report was endorsed by 14 experts and peer-reviewed by 11 national and international experts. I also submitted to the committee a recent publication by five Belgian and Dutch experts, several of whom have explicitly supported the legalization of euthanasia, but express concerns about the Dutch practice in the context of dementia.[2] The article provides an updated review of the issues raised by the Dutch practice and recommends against introducing it in Belgium. Belgium legalized euthanasia in 2002 and has not deemed it appropriate to follow the Dutch approach. It only allows euthanasia/MAID based on advance requests in situations where patients have become permanently unconscious.

Questions were raised about my reference to 'surreptitious medicating' of patients with dementia and the potential use of force in the euthanasia/MAID practice in the Netherlands. This has been a component of euthanasia/MAID practice in the Netherlands for persons with advanced dementia who are still conscious. The Netherlands is the only jurisdictions that

[1] The Expert Panel Working Group on Advance Requests for MAID, *The State of Knowledge on Advance Requests for Medical Assistance in Dying*. (Ottawa (ON): Council of Canadian Academies, 2018).
[2] J. Versijpt *et al.*, "Euthanasie bij dementia middels een voorafgaande wilsverklaring: een reflectie vanuit België en Nederland" (2022) 4 *Tijdschrift voor Geneeskunde en Gezondheidszorg* 1 doi.org/10.47671/TVG.77.21.199 [Euthanasia in situations of dementia based on an advance declaration: a reflection from Belgium and the Netherlands]

allows this practice. It is discussed in those terms in the CCA report,[3] has been reported in case reports by the Dutch Regional Review Committees,[4] and has been documented in detail in the Dutch judicial proceedings that resulted in a 2019 Hoge Raad (Dutch Supreme Court) decision known as 'The Coffee Judgment,"[5] which gave the controversial practice a legal endorsement.

Dutch scholars have described the procedure at issue in the 'Coffee Judgment' as follows:

> In order to avoid confusion and (apparent) resistance the physician sedated the patient before the euthanasia, mixing the sedative in the patient's morning coffee. These steps were discussed in advance with the family. The actual euthanasia was not discussed with the patient at that time, and the patient did not know she was about to die. During the performance of the euthanasia, the patient did respond physically to the administration of the medication, by sitting up despite the sedative. The patient was restrained by her family during the further performance of the euthanasia.[6]

This and some similar cases have been the subject of intense public debate in the Dutch medical community and society at large.[7] The practice has been critically discussed by other Dutch and international legal and ethics commentators.[8] I can provide further information to

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[3] The Expert Panel Working Group on Advance Requests for MAID, *supra* note 1 at p. 74, where it refers to "the *surreptitious* administration of a sedative in a decisionally incapacitated patient with severe dementia" (my emphasis).

[4] The Regional Review Commissions publish a selection of the due care evaluations they conduct, a practice which contrasts sharply in terms of transparency (and level of review) with what we currently have in place in Canada. For a report of a case involving 'premedicatie', as the Commissions term it, see https://www.euthanasiecommissie.nl/uitspraken/publicaties/oordelen/2020/2020-101-e.v/oordeel-2020-118

[5] HR ECLI:NL:PHR:2019: 1338 (17-12-2019) online: https://linkeddata.overheid.nl/front/portal/document-viewer?ext-id=ECLI:NL:PHR:2019:1338

[6] Eva Constance Alida Asscher & Suzanne van de Vathorst, "First prosecution of a Dutch doctor since the Euthanasia Act of 2002: what does the verdict mean?" (2020) 46:2 J Med Ethics 71–75. https://jme.bmj.com/content/46/2/71

[7] "Artsen worstelen met euthanasie bij gevorderde dementie", online: <https://www.medischcontact.nl/nieuws/laatste-nieuws/artikel/artsen-worstelen-met-euthanasie-bij-gevorderde-dementie.htm>. See also Jaap Schuurmans et al, "Euthanasia requests in dementia cases; what are experiences and needs of Dutch physicians? A qualitative interview study" (2019) 20(1) BMC Med Ethics 66.

[8] See e.g. David G. Miller *et al.*, "Advance euthanasia directives: a controversial case and its ethical implications" (2019) 45(2) 84-89; Britta van Beers, "Staat van verwarring: Over euthanasie, vergevorderde dementia en het recht op leven" [State of confusion: About euthanasia, advanced dementia, and the right to life] *Ars Aequi* (February 2020) 141-149. Online: https://arsaequi.nl/product/staat-van-verwarring/

the Committee about the Dutch and Belgian experience, which I have studied and followed closely, facilitated by my mastery of Dutch and French.

With respect to 'surreptitious medicating':[9] hundreds of Dutch physicians (including many geriatricians, and euthanasia [MAID]-consultants and euthanasia practitioners) signed a petition calling for a halt to the practice of euthanasia with "stiekem" [surreptitious] medicating of patients and made a promise to their patients that they will never end their life when they can no longer confirm their consent.[10] They strongly resist the practice. I translated into English an article in which psychiatrist Boudewijn Chabot, who overall supports legalized euthanasia/MAID, discusses the concerns about the expansion of it with regards to persons with dementia and mental health, and the Dutch debate about it.[11] The CCA report references Chabot's article and other publications and reports on this debate.[12]

2) <u>Compatibility of Advance Requests for MAID with International Human Rights Norms and the Charter.</u>

Questions were asked about my claim that MAID on the basis of advance requests violates the *Charter* and that contemporaneous consent is "arguably constitutionally required if we take the emphasis on *clear* consent in *Carter* seriously". This is connected to the point that advance requests for MAID inevitably introduce some form of third-party consent to perform a life-ending procedure, as the CCA report states,[13] and thus blurs the line between voluntary and involuntary MAID. Of course, *Carter* does not *explicitly* prohibit MAID based on advance requests, since that was not before the court. But the Court went out of its way to emphasize that "clear consent" was a vital component of allowing *some form* of MAID in the *restricted circumstances* where it needed to be allowed.

First, it explicitly restricted the scope of its decision to "the factual circumstances in this case"--a person with ALS able to confirm consent--and emphasized it made "*no pronouncement on*

[9] The term "surreptitious" is a translation of the term 'stiekem' used by Dutch practitioners (see *infra* note 7), and is used in the CCA report and in English publications discussing the practice. See e.g. the peer-reviewed discussion of cases in David G. Miller & Scott Y. H. Kim, "Euthanasia and physician-assisted suicide not meeting due care criteria in the Netherlands: a qualitative review of review committee judgements" (2017) 7:10 BMJ Open e017628."In case 2016-85, in which the *patient was surreptitiously given sedatives and later held down in order to administer more drugs,* the physician justified her actions, saying that she would have performed EAS 'even if the patient had said at that moment: "I don't want to die."

[10] Boudewijn Chabot, Piet van Leeuwen & Jaap Schuurmans, "Niet stiekem bij dementie", online: <http://nietstiekembijdementie.nl/>.

[11] Boudewijn Chabot, "Worrisome Culture Shift in the Context of Self-Selected Death", *NRC Handelsblad* (16 June 2017), online: <https://trudolemmens.wordpress.com/2017/06/19/the-euthanasia-genie-is-out-of-the-bottle-by-boudewijn-chabot-translation/>. [my translation officially approved by Dr. Chabot]

[12] *Supra* note 1 at 74, 117, 118.

[13] The CCA report states: "ARs for MAID differ from advance directives in that they inevitably involve a third party who must, based on a documented request, determine the exact timing and circumstances of a person's death." *Ibid.* at 39.

other situations where [MAID] may be sought."[14] The Court confirmed the validity of a criminal law prohibition on ending another person's life. Secondly, it stated that "euthanasia for minors or persons with psychiatric disorders" did "not fall within the parameters" of its ruling,[15] which at least means situations of cognitive disability and cognitive decline were not considered in *Carter* to be a necessary part of what the Supreme Court considered a required exemption to the prohibition to end another person's life.

Thirdly, the Court said that some problematic cases were the result of "an oversight body exercising discretion in the interpretation of the safeguards and restrictions in the Belgian legislative regime--a discretion the Belgian Parliament has not moved to restrict." [16] It hereby explicitly confirmed that a Canadian legislative regime could avoid this and be more restrictive. Interestingly, when it comes to advance requests, Belgium only allows them for euthanasia/MAID when a person has become permanently unconscious, to avoid the type of ambiguity that surrounds the Dutch practice. Canada will move further *beyond* that, and already allows it in broader circumstances than Belgium.

Fourthly, the court acknowledged that safeguards, beyond those of normal medical practice, were key, thus undermining the argument that advance requests for MAID are permissible because they *resemble* advance directives in medical practice. It should be noted, as the CCA report does, that there is a fundamental difference between advance requests for MAID and advance directives in end-of-life care: "Practitioner-administered MAID fundamentally involves invading a person's bodily integrity. That is, an AR for MAID is a request for an intervention that specifically ends the life of another person".[17] This contrasts with an advance directive related to withholding life-saving treatment, which involves abstaining from bodily invasion. In situations of uncertainty about whether a person may still be committed to a prior decision, it is more reasonable to abstain from invading a person's body than to invade; invasion without proper consent is always an assault, unlike abstention.

Finally, the Court emphasized that MAID had to be available for a "*competent* adult" who '*clearly* consents', and approvingly cited Justice Smith's statement that it would *only be ethical* when causing death is "*clearly consistent with the patient's wishes and best interests*". The qualifiers 'clearly' and 'competent' are there for a reason.

Dutch legal scholars have argued that their practice violates the right to life under the European Convention on Human Rights,[18] precisely because of the inherent ambiguity that surrounds the practice, which has been revealed also by detailed media reports of some cases in the Netherlands. [19] The inherent ambiguity is also documented in the CCA report, which

[14] *Carter v Canada (AG)* 215 SCR 331 at para. 127
[15] *Ibid.* at para. 111.
[16] *Ibid.* at para. 113.
[17] *Supra* note 1 at 38.
[18] van Beers, *supra* note 8.
[19] For an interesting example documented in a media report in the Netherlands, see Evelien van Veen, "Dat is pa niet, het is de Alzheimer die klinkt" [That's not dad, that's the Alzheimer's speaking] De Volkskrant (18 May 2018) online https://www.volkskrant.nl/mensen/dat-is-pa-niet-

discusses how this is the reason why it is already difficult to implement and to give legal effect to advance directives in normal medical practice.[20]

This is also why the practice violates in my opinion the *International Convention on the Rights of Persons with Disabilities*, in particular article 12 (equal recognition before the law), article 5 (equal protection), and article 10 (right to life). Comment 1 of the United Nations Committee of the Rights of Persons with Disabilities warns that "persons with cognitive or psychosocial disabilities have been, and still are, disproportionately affected by substitute decision-making regimes and denial of legal capacity" and that a disability, including a cognitive disability, should never be a "grounds for denying legal capacity."[21] Although the UNCRPD recognizes the value of advance planning, it strongly emphasizes an ongoing obligation to involve a person with cognitive disability in decision making, and to respect the will of the person. Surreptitious medicating and ending life without directly stimulating the person's involvement in a most crucial decision, even if it is through non-verbal means, and this at the very moment that the decision to end their life is being made, clearly runs counter to that requirement. The practice of MAID in persons with advanced dementia involves suppressing, not encouraging participation in decision-making. The committee also warns about the danger of undue influence on decision-making and the danger of abuse when persons have cognitive disabilities.

Some may argue that our Canadian law already prevents the disturbing practice of providing MAID to someone who resists. Following Bill C-7, our criminal code stipulates that a health care provider can only provide a substance to cause death if "the person does not demonstrate, by words, sounds or gestures, refusal to have the substance administered or resistance to its administration" (S. 241.2 (3.2) (c)).[22] This is likely meant to address the concern about potential resistance by persons who can no longer consent. But this alleged safeguard is undermined by S. 241.2 (3.3): "For greater certainty, involuntary words, sounds or gestures made in response to contact *do not* constitute a demonstration of refusal or

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het-is-de-alzheimer-die-klinkt~bc7a61d0/?referrer=https%3A%2F%2Ftrudolemmens.wordpress.com%2F My translation available online: https://trudolemmens.wordpress.com/2018/07/14/thats-not-dad-thats-the-alzheimers-that-sounds-by-evelien-van-veen/

[20] See the discussion in *supra* note 1 at 85-105.

[21] Committee on the Rights of Persons with Disabilities, General Comment No. 1 – Article 12: Equal Recognition Before the Law, UN Doc. No. CRPD/C/GC/1, adopted at the 11th Session (April 2014), at para 9. https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no-1-article-12-equal-recognition-1. See e.g. the discussion in Anna Arstein-Kerslake & Eilionóir Flynn, "The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: A Roadmap for Equality Before the Law" (2016) 20(4) International Journal of Human Rights 471.

[22] Criminal Code (R.S.C., 1985, c. C-46). See also S. 241.2 (3.4): Once a person demonstrates, by words, sounds or gestures, in accordance with subsection (3.2), refusal to have the substance administered or resistance to its administration, medical assistance in dying can no longer be provided to them on the basis of the consent given by them under subparagraph (3.2)(a)(iv).

resistance for the purposes of paragraph (3.2)(c).” This removes the limited protection offered by S.241.2 (3.2)(c).

A person who is performing a life-ending procedure of a now incapacitated person can *always* easily conclude that the words, sounds, or gestures were involuntary, since a finding of incapacity overlaps with a finding of lack of voluntariness. The law thus disturbingly allows health care providers to end the life of patients who physically and in sound or words resist and are deemed no longer capable of decision-making, by facilitating a conclusion that the person’s resistance to the procedure to end her life is involuntary. Health care providers who already came to the conclusion that the person is now suffering unbearable, based on a prior statement, will more likely be biased towards interpreting these reactions as involuntary. If the recommendation of some is followed, this will be expanded in very broad circumstances when a person indicates, even prior to a diagnosis, that they would want to have MAID, for example when not recognizing family members, or in other inherently nebulous circumstances.

Note that the law remains silent about surreptitious medicating of patients. This problematic practice has been documented and continues to occur in medical practice, but the consequences are obviously of an extreme seriousness when it is used to avoid any form of expression of disagreement about the ending of the person’s life.[23]

For all these reasons, I urge the committee to recommend against the expansion of advance requests for MAID, and to urge a serious reconsideration of how the more limited form of advance request already introduced through Bill C7 violates constitutional and international human rights norms.

[23] C. Tess Sheldon, “Proof in the Pudding: The Value of a Rights Based Approach to Understanding the Covert Administration of Psychotropic Medication to Adult Inpatients Determined to be Decisionally-incapable in Ontario’s Psychiatric Setting, (2017) 45(2) Journal of Law, Medicine & Ethics, 170-181 & Trudo Lemmens & C. Tess Sheldon, “The Governance of the Safety and Efficacy of Psychopharmaceuticals: Challenges and Opportunities for Reform” in J. Chandler & Colleen Flood (eds), *Law and Mind: Mental Health Law and Policy in Canada* (LexisNexis 2016) 223.