

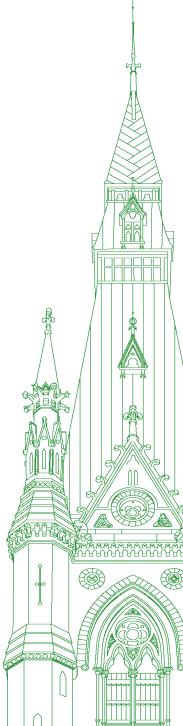
43rd PARLIAMENT, 2nd SESSION

Special Joint Committee on Medical Assistance in Dying

EVIDENCE

NUMBER 003

Monday, June 21, 2021



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• (1830)

[Translation]

The Joint Chair (Hon. Yonah Martin (Senator, British Columbia, C)): Good evening and welcome to this meeting of the Special Joint Committee on Medical Assistance in Dying.

I welcome the committee members, witnesses and members of the public who are watching the meeting online.

I am Senator Yonah Martin, and I am the joint chair of this committee, just like member of Parliament Hedy Fry.

Today, we are continuing our statutory review of the provisions of the Criminal Code relating to medical assistance in dying and their application.

[English]

Before we begin, I'd like to remind members and witnesses to keep their microphones muted at all times unless they are recognized by name by the joint chair. I remind everyone that all comments should be addressed through the joint chairs.

When you are speaking, please speak slowly and clearly. Interpretation in this video conference will work as it does at an in-person committee meeting. You have the choice at the bottom of your screen of either English or French audio.

This is the point that my co-chair was alluding to. We will end at 8:20 this evening due to votes in the House of Commons at 8:30. If there are other votes in either chamber during our meeting, we will suspend the committee briefly, and as I said, if I need to leave a little earlier due to events in the Senate, then my co-chair will graciously continue where I leave off.

With that, I would like to welcome our witnesses for panel one. We have, appearing as individuals, Dr. Jocelyn Downie, James S. Palmer chair in public policy and law, Schulich School of Law, Dalhousie University and Dr. Trudo Lemmens, professor, Scholl chair, health law and policy, Faculty of Law, University of Toronto.

Thank you for joining us.

We will begin with opening remarks by Dr. Downie, followed by Dr. Lemmens.

You each have five minutes. The floor is now yours. Thank you.

• (1835)

Dr. Jocelyn Downie (James S. Palmer Chair in Public Policy and Law, Schulich School of Law, Dalhousie University, As an

Individual): Thank you and good evening. Thank you for the invitation to be here.

As you heard, I'm Jocelyn Downie. I am the Palmer chair in public policy and law at Dalhousie University. I've been a legal academic researching and writing on medical assistance in dying for a long time, and have been intimately involved in many of the prior processes relating to the topics that are before you as a committee. I offer my comments tonight against that backdrop.

On your process, for both phases of your work, I have two hopes and challenges to offer. My first hope and challenge is that you build on the work done by those who have gone before. This includes legislative committees, court cases, expert panels and official data collectors. I hope every member of the committee will read all of these reports and decisions. I don't say that lightly. I appreciate that it's a lot, but it's worth it. You will then understand how and why we got here and have a good foundation to consider the questions about how we should move forward. Don't reinvent the wheel or rely on what other people tell you these primary sources said. This is especially true of the Carter decision.

My second hope and challenge is that you deliberately and explicitly make evidence-informed recommendations using rigorous standards of evidence. This means following the pyramid of reliability, which is appended to the opening statement that I sent to the clerk. It also means looking to the considerable body of peer-reviewed and court-tested evidence about MAID in Canada. There is no need or justification to make recommendations based on anecdotes or untested narratives. Where there are gaps in reliable evidence, don't fill those gaps with unreliable evidence and use that to inform your recommendations. Rather, call for and facilitate more research.

Now, on the substance of what you have set out for phase one, I have seven points to get on the table and into the record before we get into what you want to talk about. For obvious reasons, I will limit myself to issues of federal jurisdiction.

First, there has not been a slippery slope. The recent change to the eligibility criteria merely returns us to the Supreme Court's Carter boundaries.

Second, as you heard from Health Canada two weeks ago, the number of cases is going up, but that's what you would expect when something becomes legal, awareness goes up, access goes up, stigma goes down and the numbers go up. It's not a bad thing.

Third, the high-quality data about the involvement of and access to palliative care and social and economic vulnerability do not support the concerns raised about these during legislative debates. The data reflect a similar phenomenon to that observed in other permissive jurisdictions. Those who access MAID are disproportionately privileged as opposed to socially or economically vulnerable.

Fourth, several problems with Bill C-14 became evident through the period of implementation and were corrected by Bill C-7—notably, reducing the number of witnesses, removing the 10-day waiting period and introducing what's known as the final consent waiver. The most egregious unconstitutionality was remedied by removing "reasonably foreseeable" as an eligibility criterion.

Fifth, please do not misunderstand or misstate the meaning of "natural death has become reasonably foreseeable". This phrase did not and does not mean "terminally ill" or "imminently dying". Rather, as the Minister of Justice himself has explicitly confirmed, it means what it had come to be understood to mean in clinical practice, and that is, most definitely, not terminally ill or imminently dying. Rather, it means "with sufficient temporal proximity"—which could be years—or "on a predictable trajectory"—which could mean the diagnosis with ALS.

Sixth, MAID in prisons needs and deserves your attention during phase one. I hope you will call as witnesses Correctional Service Canada, the correctional investigator of Canada, University of Calgary professor Jessica Shaw, and Dalhousie University professor Adelina Iftene. They can explain the problems and suggest—or receive, in the case of CSC—solutions.

Finally, I hope you will recommend that the federal government use its convening power and the power of the purse to encourage, catalyze and facilitate essential research. Our courts and policy-makers benefited enormously from the unique Dutch approach to MAID research, most notably their five-year death certificate studies. We could pay it forward to other countries and avoid having our policy debates go in endless circles if we did such research ourselves. That means government-commissioned and -funded, yet independently conducted research. Without a doubt there are challenges—the variability in our death certificates, for one—but they are not insurmountable.

• (1840)

Thank you for your attention, and I look forward to your questions and comments.

The Joint Chair (Hon. Yonah Martin): Thank you, Dr. Downie. You actually corrected me because I forgot to start the stopwatch on time, so thank you very much for ending on time.

I will now invite to Dr. Lemmens to give his testimony for five minutes.

Dr. Trudo Lemmens (Professor, Scholl Chair in Health Law and Policy, Faculty of Law, University of Toronto, As an Individual): Chairs and members of the committee, I appreciate the invitation to present today as part of this parliamentary review.

In this polarized debate, where some frame all concerns about MAID as religion based, let me first firmly state that my approach is based on human rights and with respect for the equal rights and

dignity of persons who are ill, elderly and disabled and with the recognition of the state's duty to protect against premature death, which is recognized in Carter. It's informed by decades of work on professional regulation, health governance, health and human rights, and end-of-life law.

A review of these new practices from a health governance perspective is laudable. Unfortunately, Parliament put the cart before the horse by expanding the law prior to a serious evaluation of our current practice. Imagine that we decide to allow a novel form of gene therapy for serious and untreatable conditions, but prior to undertaking a legislatively mandated, five-year, solid review of the risk-benefit ratio, we introduce it as a standard form of therapy largely available on demand.

I definitely have concerns about this review, particularly about the premise from which it will start. In any area of policy-making, it is hard to scale back a practice once there is an official, professed confidence in it. It is also hard to change behaviour and expectations once a procedure is promoted and normalized, and to design post-factum structures to uncover problems and to identify lacunae, particularly when a practice leaves so much flexibility and relies heavily on the integrity of professionals committed to the practice.

I urge the committee to take a step back and remember how the B.C. Supreme Court in Carter, which lies at the foundation of our current practice, stated—with references to choice, indeed, but also the best interest of the patient—that "if it is ever ethical...for a physician to assist in death, it would be only in limited and exceptional circumstances.... The concern about imposing stringent limits stems from the consensus that unlimited physician-assisted death would pose serious risks."

The committee should be willing to question whether the current practice respects this and what even further expansion would mean. It should do more than review the statistical, largely self-reported data and the limited analyses that have been undertaken. It should take the time to listen to family members who have had bad experiences with the rushed MAID of loved ones and to people who are already struggling in our health care and social support systems, particularly during the pandemic, and for whom offers of MAID are often received as a threat to their well-being.

The committee should hear from Jonathan Marchand, a man with ALS, who complained before the Senate about his lack of health care choices; from the family members of Chris Gladders, who received MAID in shockingly dehumanizing, squalid circumstances; from Roger Foley, who was offered MAID instead of access to good care; from the family of Alan Nichols; and about other more recent cases that are emerging. It should take seriously the voices of people with disabilities who experience the explicit promotion of MAID as a confirmation that our society prioritizes ending their lives rather than providing adequate supports and care.

I urge you to be imaginative and ask how societal and legal endorsements of a broad MAID practice may already be impacting what we think our elderly and people with disabilities should do when they struggle and when solutions to their sufferings are complex and not immediately forthcoming. How will this impact how they think about what they should be doing when faced with old age, frailty and disability?

I urge you to keep in mind the challenging health issues that indigenous people and racialized Canadians disproportionately face, the revolting situation of many of our elderly in long-term care homes, exposed during the pandemic, and the lack of choices for the elderly and people with disabilities. Think about that when exploring the risks of normalizing MAID as therapy for suffering, when critically analyzing the premise in our MAID law that capacity and informed consent procedures are already providing sufficient protection against abuse.

Many of these concerns about the impact of ableism are particularly long-term, but I already have mentioned concrete examples of current concerns. How common are these? I suggest that we need more robust data.

The first Health Canada MAID report, however, should be a wake-up call. In addition to showing the normalization of MAID through the rapid uptake—particularly in some provinces—faster than, for example, in Belgium and the Netherlands, two countries with significantly more investment in palliative care and social support, the report confirms—

The Joint Chair (Hon. Yonah Martin): You have 30 seconds.

Dr. Trudo Lemmens: —some of the concerns with our already broader than strict end-of-life practices. It documents, for example, various factors associated with unbearable suffering that lie at the basis of the more than 15,000 MAID requests. It includes fear of being a burden to family, friends and caregivers in 34% of the cases and loneliness in 14% of the cases. For 53%, it's the loss of dignity, a concept profoundly influenced by ableist perceptions that our MAID practice may stimulate; and inadequate pain control or a fear of pain are cited in 54% of cases, reflecting a possible lack of access to adequate health care and palliative care—and even in some cases existential suffering.

● (1845)

In the question period—

The Joint Chair (Hon. Yonah Martin): Dr. Lemmens, I apologize for interrupting, but hopefully you will have a chance to answer questions.

Mr. Arseneault, you are on the list for the second panel, so-

[Translation]

Mr. René Arseneault (Madawaska—Restigouche, Lib.): Madam Chair, I am a federal member of Parliament.

The interpreter said she was having trouble hearing the witness, Mr. Lemmens, and that she was just following the text. I would like this issue to be resolved, as I want to hear what Mr. Lemmens and the other witnesses are saying.

[English]

The Joint Chair (Hon. Yonah Martin): I apologize, Mr. Arseneault.

Are you not Mr. Arseneault? That's what it says on your screen. In any event—

[Translation]

Mr. René Arseneault: I am Mr. Arseneault. You asked me whether I was the next witness. I can be, but I prefer to ask questions.

[English]

The Joint Chair (Hon. Yonah Martin): No, no, I was not.... I apologize.

To the interpreters, the French translation was not as audible.

I don't know if everyone else heard Dr. Lemmens on the English channel. Okay, I see nods of heads.

Dr. Lemmens—

[Translation]

Mr. René Arseneault: The interpreter told us that, as the sound quality was poor, she was just reading the text Mr. Lemmens had prepared.

The interpreters will not have a text when we start asking questions. Interpretation is essential. The sound quality for Mr. Lemmens must be as good as it is for the other witnesses.

[English]

The Joint Chair (Hon. Yonah Martin): Yes.

May I ask the joint clerk, Mireille, whether we need to test Dr. Lemmens' sound before we continue?

The Joint Clerk of the Committee (Ms. Mireille Aubé): We have already done an audio test and we discovered some difficulties. Now the interpreters are asking if he could speak slowly the next time he answers a question. That could possibly help with the translation.

The Joint Chair (Hon. Yonah Martin): Okay. Thank you.

Dr. Lemmens, when you are speaking, please slow down and articulate as best you can. We appreciate your co-operation on this. Thank you very much.

I will move to-

Dr. Trudo Lemmens: I hope that my comments will be distributed in translation to the francophone members.

The Joint Chair (Hon. Yonah Martin): Yes, they have been distributed already. However, in your testimony today, there was some difficulty with translation.

[Translation]

Mr. Luc Thériault (Montcalm, BQ): The text has not been distributed. I was looking for the text the interpreter was reading, but we have not received it, and that is unfortunate.

We had agreed to work properly. I find it unfortunate that we don't have that text this evening. It has not been distributed.

[English]

The Joint Chair (Hon. Yonah Martin): Thank you, Mr. Théri-

May I ask Marc, the House joint clerk, whether translation of Dr. Lemmens' testimony was sent to all MPs?

The Joint Clerk of the Committee (Mr. Marc-Olivier Girard): No, it has not, unfortunately. It's not the witness's fault at all. We received said speaking notes just a few minutes prior to the start of the meeting, so we were therefore unable to get them translated on time for the members.

As for Mr. Lemmens' sound, he's unable to use the usual headset provided by the House of Commons, so he asked to use the podcast mike that you see in front of him. We have already tested him. I think it's the maximum that we can do in the circumstances.

As Mireille was saying, if it's possible to have Mr. Lemmens speak as slowly as possible, that could at least minimize the risk of losing interpretation.

I apologize, but as I mentioned, we did everything we could.

Thank you.

• (1850)

The Joint Chair (Hon. Yonah Martin): I apologize to everyone, as well, regarding the translation that wasn't sent to the MPs, and I saw Senator Kutcher....

I'm going to move on because of time, so I apologize to everyone. Thank you for your flexibility and understanding today.

Again, Dr. Lemmens, please enunciate and speak slowly, as best as possible. Thank you.

For the first round of House of Commons questions, we will have Liberal MP Arif Virani, followed by Michael Cooper of the Conservatives.

Mr. Virani, you have five minutes.

Mr. Arif Virani (Parkdale—High Park, Lib.): Thank you very much to both witnesses for being here. We appreciate your expertise and your contributing to this important study.

My questions will be for Dr. Downie.

Dr. Downie, we heard some commentary in the course of the passage of Bill C-14 on concerns about ableism, which has resurfaced today in informing the concerns about Bill C-14, specifically in respect to persons with disabilities and their concerns not having come to the fore. My view is a little different, given that in the Truchon case we had two persons with disabilities actually seeking their autonomy to be validated by the court in terms of seeking to govern and control the timing of their own passing.

Could you comment on some of these concerns with respect to ableism? Is that a fair concern from your perspective? What safeguards are currently in place for persons with disabilities under the medical assistance in dying regime?

Thank you.

Dr. Jocelyn Downie: The first thing to say about ableism is that it was the argument that was raised in the Truchon case. It was thoroughly canvassed, and the judge offered very strong analysis around that, pointing out that it is paternalistic to claim that individuals need to be protected from themselves, from basically ableism that they have somehow embraced in their own world view.

What we have to do, and what we do in the context of all of MAID, is take the view of the suffering from the perspective of the individual. It is for the person to decide what their conditions of life are, whether they value them and whether they wish to have their life end. The way you protect that is that the consent must be informed. It must be made by a person with decision-making capacity. All the alternatives have to be explored.

One of the things about Bill C-7 is that of course for track two there are additional safeguards. You have to make sure that the person has been informed about and given access to supports and services that would address some of the concerns that might be arising from their disability—from the lack of services and supports associated with their disability, as opposed to their experience of their disability. You also have a condition that it has to be "seriously considered". That's an additional test that has been put in Bill C-7 to protect against the kinds of concerns that people have raised. I'd say it's been canvassed, analyzed and adjudicated, and additional safeguards have been added to the legislation.

Mr. Arif Virani: Thank you.

I just have two and a half minutes left. I'm going to try to ask you another question.

Some of those safeguards that you mentioned answer in part what I was going to ask you next. Is it an unlimited sphere or are there safeguards in place? I think you've articulated some of the safeguards, and I think that's important.

Can you speak about the data in terms of who is accessing MAID? We've heard again this evening concerns about people being pressured into this. From my perspective, having participated in some of the consultations prior to the advent of Bill C-14, I understood MAID to be a very carefully considered and well-thought-out process that people come to after really giving it a lot of due consideration, as opposed to some sort of rushed choice.

What is your experience and how does that relate to the data you have seen insofar as who is accessing MAID in this country over the last five or so years since the advent of Bill C-14?

Dr. Jocelyn Downie: One of the first things to stress is that MAID assessors and providers have no interest in pressuring anybody into having MAID. They view their role as respecting the autonomy of the individual in front of them—not pressuring them—and as checking that there's no pressure from external sources as well, and they take that very, very seriously throughout the process of the assessment.

In terms of the data, what we have is what Abby Hoffman from Health Canada came and told you about two weeks ago, which doesn't indicate any basis for concern with respect to any kind of pressure being applied to people. Whatever data we have demonstrates now.... There's a big study out of Ontario that was also mentioned two weeks ago, and I have the reference in my notes for you. People talk about the concern that it is those who are socio-economically disadvantaged who will access MAID because of pressure or because of a lack of services. The evidence we have shows that it's quite the opposite. It is people who are privileged, just as it is in the other permissive jurisdictions. It is people who are privileged, not people who are socio-economically disadvantaged or persons with disabilities and so on.

The evidence doesn't support it and the practice that we see in talking to a body of assessors and providers.... As Justice Smith said in Carter, we rely on health care providers. We trust them for all kinds of things, and there is no reason not to trust them for this.

• (1855)

Mr. Arif Virani: Thank you so much.

I'll use my last 20 seconds to say that a very helpful amendment was suggested by Senator Jaffer when we were dealing with Bill C-7, about tracking the data, including race and ethnicity. I guess it will remain to be seen, but your hypothesis would be that it's not having a disproportionate impact on that sector.

Dr. Jocelyn Downie: That was also the point of doing death certificate studies.

The Joint Chair (Hon. Yonah Martin): Thank you, Mr. Virani.

Next we have Michael Cooper, followed by Bloc MP Luc Thériault.

Mr. Michael Cooper (St. Albert—Edmonton, CPC): Thank you, Madam Co-Chair, and thank you, Dr. Downie and Dr. Lemmens.

My questions are for Dr. Lemmens.

Dr. Romayne Gallagher, a palliative care physician and professor at the faculty of medicine at the University of British Columbia, wrote a paper arguing that in many instances, MAID should be considered a medical error, because the suffering that led to MAID could have been alleviated with palliative care and other methods of support.

Having regard for the Health Canada report, and in particular the table indicating the frequency of 11 types of intolerable suffering, would you care to comment on that?

The Joint Chair (Hon. Yonah Martin): Dr. Lemmens?

I think there are some issues with the sound. Could you unmute?

Dr. Trudo Lemmens: Yes. If it was a question for me, I was on the phone with the House of Commons. I called in today to test this.

The Joint Chair (Hon. Yonah Martin): Michael, could you just quickly repeat your question? You may have time for only this one question, so go ahead.

Hon. Kerry-Lynne Findlay (South Surrey—White Rock, CPC): I have a point of order, Madam Chair. We would never normally dock time for technical problems. I don't think that's fair at all to suggest that the time is restricted when someone didn't hear the question. That's not appropriate.

The Joint Chair (Hon. Yonah Martin): I apologize. Our time is ticking as we go. I'll just ask Michael Cooper to repeat his question, and I guess Dr. Lemmens will receive a call from the House of Commons.

I hope colleagues are agreeable that it was not the fault of Dr. Lemmens that a call came from the House of Commons. I'm sure it's all sound-related.

I will ask Michael Cooper to repeat his question. I think about 30 seconds was lost in my exchange, so I will add that time. Thank

Go ahead, Michael Cooper.

Mr. Michael Cooper: Thank you again, Madam Co-Chair.

Dr. Lemmens, Dr. Romayne Gallagher, a palliative care physician and member of the faculty of medicine at the University of British Columbia, wrote a paper in which she argued that in many cases of MAID, it should be considered a medical error on the basis that the suffering that led to that request could have been alleviated with palliative care and other methods of support.

Having regard for the Health Canada report, and the table listing the 11 types of intolerable suffering, and the frequency of such suffering in the course of making a MAID request, would you care to comment on that? **Dr. Trudo Lemmens:** Indeed, the Health Canada report and other studies that have been undertaken and are published in the peer-reviewed literature suggest that many people who are receiving MAID in Canada—it's not the majority, but still a substantial number of people—have not had access to adequate palliative care.

There are studies that are more positive. The Downar peer-reviewed study is the most positive about access to palliative care, but it does not discuss in detail what the quality of palliative care was or whether the palliative care offered was of sufficient quality.

The Health Canada report also suggests that 19% of people, for example, had access to palliative care only in the last two weeks before they received MAID. Another 19% actually received it only in the last month.

If you can speak to the palliative care specialists, as I'm sure you will, I'm pretty confident they will state that palliative care takes time. It takes time to offer alternatives to people.

The messages we get from the reports and from the data are not overwhelmingly, "Oh, we have a perfect situation here where people have access to perfect palliative care."

We know from the data that palliative care is lacking in many Canadian provinces and adequate palliative care is lacking in many Canadian provinces, and that significant improvements can be made in that context.

• (1900)

Mr. Michael Cooper: Thank you, Dr. Lemmens.

I'll ask a question on the Health Canada report with respect to the table listing intolerable suffering. The report focuses on that, but it provides no evidence whatsoever of the other elements required in order to qualify for MAID, including a serious incurable illness, that one is in an advanced state of decline, and that death is reasonably foreseeable, which was a requirement pre Bill C-7.

The report mentions none of that. We know there have been several well-documented instances of abuse, and yet nowhere is that even acknowledged in the Health Canada report. Could you comment on that?

The Joint Chair (Hon. Yonah Martin): Dr. Lemmens, you have about 45 seconds.

Dr. Trudo Lemmens: I ask the committee members to be imaginative. Reporting is self-reported data. Because I have written some op-ed pieces that are critical of some components of MAID, I receive spontaneous requests from people who share their experiences, who ask for advice. I send them to lawyers.

If you have worked on professional regulations, you know that claiming or filing complaints and actually obtaining accountability in the context of health professional mishaps is extremely difficult. It is extremely difficult to—

The Joint Chair (Hon. Yonah Martin): Thank you very much, Dr. Lemmens.

We have next MP Luc Thériault, followed by Jenny Kwan.

[Translation]

Mr. Luc Thériault: Thank you very much.

Professor Downie, thank you for your forecast, which is important this early in the study.

I want to tell you that I have been following your statements with much interest. I would like to get more information on your first point, where you say that there is no slippery slope. Unlike your other points, this one did not come with an explanatory note.

[English]

Dr. Jocelyn Downie: Absolutely. That is because it's a legal claim.

The eligibility criteria, which started out as a grievous and irremediable medical condition in Carter, were shrunk by Bill C-14, and then with Truchon were put back almost all the way to Carter. There's no slippery slope beyond Carter; we haven't gone beyond Carter.

The footnotes to the Truchon decision, I suppose, and to the Carter decision, would have been to show that the eligibility criteria, by taking out "reasonably foreseeable", and certainly in Quebec, "end of life".... It actually doesn't take you beyond Carter. I don't think we've had an expansion of the eligibility criteria for MAID in Canada.

[Translation]

Mr. Luc Thériault: Am I also to understand that you think it was wise not to challenge the Truchon decision, not to appeal it and not to continue the legal process?

• (1905)

[English]

Dr. Jocelyn Downie: Absolutely. It's consistent with the early arguments that were made by Joe Arvay and Ménard and so on, that Bill C-14 was unconstitutional. Then you had a very strong decision from Madam Justice Beaudoin: Don't appeal. Just get on with implementing MAID.

The Joint Chair (Hon. Yonah Martin): Mr. Thériault.

[Translation]

Mr. Luc Thériault: I will now address your fifth point. You say that the concept of a reasonably foreseeable natural death refers to a predictable trajectory, but does not mean "terminally ill" or "imminently dying".

However, that criterion has been removed from Bill C-7 because, on the one hand, it is not a medical criterion and, on the other hand, it was creating confusion. At the same time, that concept is sort of back in the bill, as two distinct safeguard tracks are involved: for terminal illness where the end is near, with death being irremediable; and for terminal illness that may last seven years. Isn't that how the community talks about this: an imminent predictable death, such as in three months' time, as opposed to a predictable death, but only after a few years in end stage?

I don't know whether I have enough time left, but the Senate report talks about euthanasia and assisted suicide. There is a reason for that, as it is said that euthanasia applies to people in end stage, while assisted suicide is intended for individuals suffering from a degenerative disease who are experiencing intolerable suffering, even if the time of their death is still unknown. Why do you want that distinction to be removed, not in the legislation, but conceptually speaking? Wouldn't expanding that notion undermine advance requests?

[English]

Dr. Jocelyn Downie: It's essential to be super clear on this. Track one, track two: the distinction is whether natural death is reasonably foreseeable. The minister has made it very clear that "reasonably foreseeable" means what it meant before C-7, and it did not mean terminally ill or imminently dying. That's very, very clear.

It isn't that track one is only for terminally ill people—

The Joint Chair (Hon. Yonah Martin): Thank you, Dr. Downie. We'll end it there. I hope that was the end of your first statement.

We're going to go to Jenny Kwan for five minutes, followed by Senator Kutcher.

Ms. Jenny Kwan (Vancouver East, NDP): Thank you very much, Madam Chair.

Thank you to the witnesses for their presentations.

My first question is for you, Dr. Downie.

Health Canada's first annual report on medical assistance in dying in Canada stated:

Data linkages which would allow for more in-depth examinations of the social circumstances of persons requesting MAID (such as geography), are also being considered to support improved practice and policy decisions for social services and for health care systems.

In your written submission, you stated:

The high-quality data re: involvement of, and access to, palliative care and social and economic vulnerability do not support the concerns raised about these during legislative debates. The data reflect a similar phenomenon to that observed in other permissive jurisdictions—those who access MAiD are disproportionately privileged as opposed to socially or economically vulnerable.

Can you please expand on what you were referring to in this section of your written brief? There has been misinformation perpetuated through debates, and you encourage taking an evidence-based approach. What has your research revealed about palliative care or access to MAID for socially or economically vulnerable populations? Will the new data provisions brought in under Bill C-7 help identify gaps in proportionality?

• (1910)

Dr. Jocelyn Downie: I'll start where you ended. The new regulations are going to be very, very helpful in exactly these kinds of issues. There are two things. One, they're going to expand what they're looking for, as was passed in Bill C-7. The other is that Health Canada, as I understand it, is looking to make linkages between databases possible. There should be something coming out on that in the fall, I believe.

That will help us get more data. I haven't said we have sufficient data yet. What I've commented on is that the data we have doesn't

yet demonstrate what people are expressing as concerns about vulnerability. We have the big study out of Ontario, which was all of the MAID deaths between June 7, 2016, to October 31, 2018. Then there was another study, the Redelmeier paper, which was also referenced in there.

That's the best data we have. It is high-quality data. It demonstrates the point I made, which is that it's a practice of privilege at this point. There is reason to be concerned, actually, about the lack of access for people who are socially and economically disadvantaged as opposed to inappropriate access or too much access. I fully support more research. I hope one of your recommendations will be to follow the Dutch model. Look at the Dutch versus the Belgian approach to getting the data. They do something similar in terms of death certificate studies. In the Netherlands it's funded by the government and then done by independent researchers. In Belgium the researchers have to go and find the research funding to do it. As a result, it's much more uneven in Belgium than it is in the Netherlands. It's like clockwork, every five years, out of the Netherlands, with amazing response rates. It's really, really robust data.

Look to the Dutch researchers, who've been doing this for 25-plus years, for how to do it. That will get us even more of the information we need than will be available through the Health Canada process.

Ms. Jenny Kwan: Thank you very much. That's very helpful.

With respect to the list of essential reading that was appended to your submission, you included the 2018 report by the Council of Canadian Academies' expert panel on medical assistance in dying. In that report, it was mentioned that the early planning meetings, particularly in the section dealing with mental disorder as the sole underlying—

The Joint Chair (Hon. Yonah Martin): You have one minute remaining.

Ms. Jenny Kwan: With respect to that issue, can you provide more details for the committee on some of the challenging areas identified by the working group, where there were disagreements? Can you expand on that a bit for the committee's benefit?

Dr. Jocelyn Downie: Well, it's phase two, so you will be coming back to this. That's why I didn't go into it in my actual remarks. Concerns that have been expressed about mental illness—debates that were held in the process of the Council of Canadian Academies—relate to "irremediably". Can you assess capacity? Is there discrimination against persons with mental disorders if you don't allow them to have access? All those issues were canvassed.

They're also in Truchon. Everything was tested in the Truchon case. All of these concerns about mental disorders were tested in the Truchon case.

The Joint Chair (Hon. Yonah Martin): Thank you. That was perfect timing.

We will go to questions from Senator Kutcher and then Senator Wallin, as Senator Dalphond is not here.

You have three minutes. Thank you.

Hon. Stanley Kutcher (Senator, Nova Scotia, ISG): Thank you, Madam Chair.

Professor Downie, I want to pick up where our colleague Mr. Thériault left off, on the importance of using the best data we have. Thank you for underscoring that, and that the plural of anecdote is not "data".

In the Carter criteria for MAID access, consideration was the phrase "grievous and irremediable" condition. Given your extensive study of this issue, what does this phrase mean? Who ultimately decides if a condition is grievous and irremediable?

I then have a second question.

Dr. Jocelyn Downie: I don't think the government got it wrong when they defined it as illness, disease or disability. They tried to give clarity to the concept of condition. That's what we have, and I think that's what we should continue to work with.

As to who decides if it's grievous and irremediable, it is for the person to decide if their suffering cannot be relieved by any means that are acceptable to them. Suffering is subjective. Now, the clinician can determine whether a person's condition can be alleviated by the provision of antibiotics, for instance, or by surgery. That is an object of clinical determination.

It's a mix, given that "grievous and irremediable condition" includes both the suffering and the incurability or the severity of the condition or the irreversibility of the decline in capability. It is essential that we remember that it is subjective, the assessment of suffering, and what treatment people are willing to take.

• (1915)

The Joint Chair (Hon. Yonah Martin): About half of your time has gone, Senator.

Hon. Stanley Kutcher: Okay, thank you.

Do you think that with the passage of Bill C-7, the Government of Canada has now fully complied with both the Carter and Truchon decisions?

Dr. Jocelyn Downie: Because of the presence of the sunset clause, I say yes. If the sunset clause had not been there I would have said no, because it discriminates on the basis of mental disorder. Yes, I think it is completely compliant with Truchon and Carter. I think that your phase two will still be the "mature minors" issue, but that's a charter issue, not a Carter issue.

Hon. Stanley Kutcher: Thank you for that.

In your extensive experience on this topic, are you familiar with the solid data that shows that MAID providers are actually trying to pressure individuals to receive MAID?

Dr. Jocelyn Downie: I have seen no evidence whatsoever that that has been tested. People have made allegations, but never have those been tested in front of a college of physicians and surgeons or a court, so no.

Hon. Stanley Kutcher: Thank you.

The Joint Chair (Hon. Yonah Martin): Thank you.

Senator Wallin.

Hon. Pamela Wallin (Senator, Saskatchewan, CSG): Thank you.

Just to follow up on Senator Kutcher's note that anecdotes do not equal data, is there, in your mind, a serious number of MAID requests that have been put forward due to lack of access to palliative care?

Dr. Jocelyn Downie: There is absolutely not evidence of that. One thing that happens is when you request palliative care.... If you happen to be in a position where you haven't been offered palliative care before and you request MAID, one thing your clinician is legally required to raise with you is the option of palliative care. It's very important to know that, to recognize it. No, people are not doing that.

Hon. Pamela Wallin: I want to just follow up on the whole question of privilege, from the other side of the coin, if you will. The concerns we hear are about lack of access depending on where people are. It may be regional, if you live in a rural setting as opposed to an urban setting. In fact, a number of people, certainly, have come to me personally. Again, that's anecdotal.

I would like to know what you know about lack of access for people requesting MAID.

Dr. Jocelyn Downie: The concern I have about lack of access is principally in relation to institutions that are not allowing MAID because they are religiously based or they are palliative care organizations that have taken the position that no MAID should happen within their walls. That is what I see as the problem. I didn't raise it, because that's a provincial jurisdictional issue, but it is a really serious concern.

The other thing I would note, and this goes to what you're concerned about, is that there are actually people who are disempowered. If they don't know about MAID or they don't feel like they have a lot of power, they aren't going to ask for it; whereas someone like me, someone like everybody on this panel, we're just going to say, "I want this." You've been out there, saying that for advance requests. We feel empowered to ask and to advocate for ourselves and to access. I think there are people who are disempowered, who aren't getting access.

Hon. Pamela Wallin: On the whole issue of advance requests, it seems to me that if that became a more common way to approach this whole issue of MAID, it would resolve that concern about whether or not people have actually chosen this freely.

The Joint Chair (Hon. Yonah Martin): I'll give you a few more seconds, Dr. Downie.

Dr. Jocelyn Downie: I think one thing it would open up is conversation about end-of-life decision-making. People can choose to end their lives in all different kinds of ways. Some will have MAID; some will not. Some will have an advance request; some will not. By being able to discuss it sooner, which is what you can do when you have an advance request, you can have the discussion with respect to palliative care and everything else earlier in the process, when people aren't desperate.

Hon. Pamela Wallin: Thank you.

The Joint Chair (Hon. Yonah Martin): Thank you.

I'm just going to use my three minutes to ask Dr. Lemmens a question. Then, actually, the bill that I'm sponsoring in the Senate is up, so I'm going to have to go right after, without hearing the answer, but I'll read the testimony.

Dr. Lemmens, you said in your testimony for Bill C-7 that the bill moves Canada beyond the most liberal MAID regimes in the world and fundamentally alters long-standing legal and ethical norms of health care practice.

I'd like you to elaborate on that statement, the concerns you have as to where Canada is, and evidence you may have that counters what you are hearing so far. Thank you.

(1920)

Dr. Trudo Lemmens: Yes. This is a quote from an article we wrote that I hope the committee members will read. It is indeed the case that in Belgium and the Netherlands physicians have to agree that there are no other reasonable options left.

In the Canadian context, with Bill C-7, we now have a requirement that physicians have to evaluate whether the patients have seriously considered that, but I would say that the obligation within the health care system to provide MAID when patients reject reasonable options for care is actually unprecedented. There are other forms of health care, like high-risk procedures, where physicians actually would not be allowed and it would be a violation of their professional standards if they immediately provided access to procedures that have an inappropriate risk-benefit balance.

It's interesting that we now have idealized the practice of ending the life of a person to the point that we actually, not just.... We obviously respect people's right to refuse treatment. That's an inherent right that people have, the right to refuse a treatment. That's based on the notion of autonomy and also the right to be free from bodily interference. In the context of MAID, we're talking about something very different. We're not just talking about the right to refuse treatment. We're talking about the insistence that we actually obtain a life-ending procedure from physicians.

Yes, it constitutes a departure from the role that physicians play in the determination of the standard of care. I think it's unprecedented. It's not in line with how even the most liberal regimes—Belgium and the Netherlands—provide access to medical assistance in dying, at least in their legal provisions.

The evidence of both Belgium and the Netherlands.... Dr. Downie says there is no evidence that vulnerable people are at risk. I would contradict that. I would say that there are clear changes that have been happening in access to medical assistance in dying in Belgium and the Netherlands in the last decade. We increasingly see people who are not close to death receiving access to medical assistance in dying, for example for the new concept of what has been termed polypathology, which is a variety of ailments. We clearly see evidence that people who are receiving MAID for mental health are people who are lonely and isolated and represent socially disadvantaged people.

I would also urge the committee to look at a recent, very large study looking at the way in which people aged over 50 in the Netherlands are increasingly inclined to ask for medical assistance in dying—euthanasia—even without a clear, identifiable illness that would provide them access under the law. The researchers who did the study sent out warnings saying they have, in that population, a very substantial number of people who are socially disadvantaged, less educated and less financially wealthy.

I would say that yes, there is evidence that suggests that in the long term, the practice has been identified in.... An early Ontario study indeed indicates that the people who asked for access to medically assisted dying in the early days were privileged, more highly educated and often in a relationship. I'm not denying that kind of evidence. That's certainly the case. It doesn't mean that there are no further risks along the road and that there are no risks in vulnerable populations, such as people with disabilities or mental illness, or socially disadvantaged people.

The Joint Chair (Hon. Hedy Fry (Vancouver Centre, Lib.)): Thank you, Professor Lemmens. I think we have come to the end of that time.

There are bells ringing in the House for votes, but we have had unanimous consent to continue for 20 minutes, so we will have 10 minutes in which to vote.

Right now I'm looking at the bells. I just wanted to give you a heads up, everyone, so you know what's going on. We have 24 minutes left and the bells. It means we have 12 minutes for the second round.

Given that Senator Martin has left, I will go to the second round quickly. That second round will begin with Mr. Arseneault, for three minutes. That includes questions and answers, so be mindful, those who are answering as well. Thank you.

• (1925)

[Translation]

Mr. René Arseneault: Thank you very much, Madam Chair.

Ms. Downie, my colleague Michael Cooper and I were members of the initial joint committee, whose work led to Bill C-7. We had to rely on practical information from other jurisdictions and other countries, which rightly caused us to be suspicious and concerned. Since then, we have received a lot of data from Canada that really reassures us about the decisions we will have to make during the study.

When you say that one of your greatest wishes is that we not make recommendations based on anecdotes or untested theories, I imagine you have an example in mind. What were you referring to when you said that?

[English]

Dr. Jocelyn Downie: I was thinking of the narratives that you see on the Internet, the stories, and even some of the names that Professor Lemmens mentioned. These are narratives that have not been tested in court, or tested in any other kind of way where we can test the evidence.

Testimonies that come before you, where you hear these horror stories as you did in the Bill C-7 hearings, are not tested. The only evidence we have that meets a quality standard doesn't demonstrate these concerns. If people want to make allegations, they have to put them to the test.

[Translation]

Mr. René Arseneault: Thank you, Ms. Downie. I don't have much time left and I have a second question for you.

We're aware of the Carter decision. The justices unanimously tell us that a person seeking medical assistance in dying must have an incurable disease that causes physical or psychological suffering and for which they are not required to obtain medication or treatment

The main argument of MAiD opponents is always that there is a lack of palliative care or that there are other options. How can this be reconciled with the Carter decision?

[English]

Dr. Jocelyn Downie: One of the things that Justice Smith noted in Carter v. Canada was that Gloria Taylor was offered palliative care and didn't want it. Gloria Taylor was at the heart of the Carter decision. Not everybody wants palliative care. Palliative care can't help everybody, but, that said, everybody should be offered palliative care.

These things go hand in glove. MAID and palliative care are not oppositional. They are part of the entire end-of-life care tool box.

The Joint Chair (Hon. Hedy Fry): You have 30 seconds, Monsieur Arseneault.

[Translation]

Mr. René Arseneault: I am going to jump around. Ms. Downie, why would prisons be given special attention, as suggested in point 6?

[English]

Dr. Jocelyn Downie: We tend to forget about prisoners. We don't care enough about them, yet they are very vulnerable in not having access to proper health care, and that includes end-of-life care. We have some reports that give us reason to be concerned about what's happening in prisons.

My concern is that they're not getting proper access. The rules aren't actually being followed. I was trying to make a plea. You're in phase one. You're supposed to be looking at implementation issues. This is an implementation issue. Look at the reports from the

office of the investigator. Let's get that cleaned up by getting a proper compassionate release program.

The Joint Chair (Hon. Hedy Fry): Thank you, Dr. Downie.

I will now go to Tamara Jansen from the Conservatives, for three minutes, please, including questions and answers.

Mrs. Tamara Jansen (Cloverdale—Langley City, CPC): Dr. Lemmens, Dr. Downie just told the committee there's no slippery slope here, and that we're not going beyond Carter. Could you respond to that? Do you agree with that statement?

Dr. Trudo Lemmens: Only somebody who has a very theoretical and artificial view of the relationship between the Supreme Court and Parliament and who ignores the complex interplay between the Supreme Court and Parliament would say that.

Her colleague, the late Professor Pothier, argued, in a piece after the Carter decision came out, that it was nonsense to argue, for example, that Parliament had no liberty to design a regulatory system with some level of liberty. The Supreme Court explicitly asked Parliament to design law.

You can argue that, yes, there were some cases following Carter. There was the Canada (Attorney General) v. E.F. case in Alberta that interpreted Carter, but in and of itself, the legislator, Parliament, and you parliamentarians, made a decision to have a law. That was the law of the land. This law has now been expanded. If that's not a legal slippery slope, I don't know what is.

• (1930)

Mrs. Tamara Jansen: Thank you.

I understand that MAID assessments are sometimes being done over the phone, with the doctor never even meeting the patient. Is there any chance in your mind that such an assessment would be able to detect things like elder abuse or coercion by family members? How is it possible that we have not seen a single instance of prosecution, with this going on?

Dr. Trudo Lemmens: Yes, that's always a problem, you know, when people say they need evidence; they need reports, they need judicial hearings and they need a judicial decision to test the evidence. That ignores, actually, the difficulty that people face with respect to access to justice in taking physicians to court and [*Inaudible—Editor*] to court. I have personally been informed of family members who told how their elderly mother was assessed as in need over the phone.

Is that appropriate? I would say that it's not appropriate, but it has been done.

Mrs. Tamara Jansen: Right. Absolutely.

The 2019 report on medical assistance in dying laid out various reasons Canadians would request MAID. Those reasons included things like fear of pain, loneliness and feeling like a burden on family. Does it make sense that we're ending people's lives for the kinds of reasons that could easily be addressed by palliative care? How difficult would it be to ensure that a patient got regular visits so they didn't feel so lonely, rather than taking the extreme measure of ending their lives?

Dr. Trudo Lemmens: I agree with Professor Downie that sometimes people may refuse certain types of care, but I am not convinced that people actually receive all of the reasonable options for care that would indeed help them change their minds. We can reject some of these stories as anecdotes, but again, we have a substantial number of people coming forward and contacting people who have been critical of some of [*Technical difficulty—Editor*] and telling us about these concerns that their family members felt, particularly during the pandemic—for example, isolated, lonely, received bad care....

The Joint Chair (Hon. Hedy Fry): Thank you, Mr. Lemmens. I think we're out of time. We have two more questioners here.

We have Monsieur Thériault for two minutes.

Monsieur Thériault, please.

[Translation]

Mr. Luc Thériault: Ms. Downie, I am going to try to put my question differently. Quebec's Act Respecting End-of-Life Care didn't cover cases like Ms. Gladu's and Mr. Truchon's, otherwise there would have been no Truchon and Gladu decision. The legislation therefore created a continuum of palliative care that allowed for a request for medical assistance in dying. Because it was considered a continuum of care, the Criminal Code didn't have to apply. Therefore, medical practice established a distinction between the terminal stage, the process of dying and other degenerative diseases.

Neither safeguard regime is specific enough. Would you agree to apply the prognosis regime in cases where death is likely to occur within 12 months, and the 90-day regime in cases where death is likely to occur after more than 12 months?

The reasonably foreseeable natural death criterion was rejected. Why return to it, since it's impossible to assess whether a death is reasonably foreseeable? On the other hand, distinguishing between a prognosis of 12 months or less and one of 12 months or more would allow us to move forward. After all, physicians are used to making prognoses.

[English]

Dr. Jocelyn Downie: First off, very quickly, to your point on end of life, Quebec was different. When I was talking before, I was talking about the difference in the federal regime. Quebec's was end of life, truly end of life, so it is a different change, absolutely.

On the idea that you can do 12 months, not 12 months...that's not actually as clear as you might think. Clinicians are terrible at deciding whether somebody has 12 months or not.

The other point is that we now have an understanding of "reasonably foreseeable", so my hope would be that Quebec will embrace

the actual federal regime, which has two tracks that are premised on reasonably foreseeable not as an eligibility criterion, because it was rejected as unconstitutional as an eligibility criterion. It acts as a decider as to which track you go on. It now has an understood meaning and it can be used to determine which track you go on as opposed to eligibility, so it's not unconstitutional. It's actually clearer than 12 months, and 12 months would be unconstitutional.

• (1935)

The Joint Chair (Hon. Hedy Fry): Thank you, Professor Downie.

I now go to Ms. Kwan for two minutes, please, for the question and the answer.

Ms. Jenny Kwan: Thank you.

I just want to go back and ask Professor Downie about the question of data. She mentioned earlier the Netherlands versus Belgium, and said that Canada can in fact learn something from that.

Do you have any sense of what kinds of resources the government in the Netherlands provided to get this research and data done?

Dr. Jocelyn Downie: I don't know the dollar amount, but you could get that by a quick call to Agnes van der Heide. She is known. She has testified before. She would have the precise numbers that go with doing that review.

I'm afraid I don't have the numbers, but I could get them.

Ms. Jenny Kwan: If you could, that would be great. If you could submit that information in a written format to the committee, and any other additional information that would be valuable for consideration for recommendations, that would be very helpful.

I only have a tiny bit of time left, so I want to give you the last few moments to respond to some of the differing opinions that were offered at committee today.

Dr. Jocelyn Downie: Yes. One, I regret that it descends to ad hominem. However, to the notion that there's no liberty for Parliament to disagree with the courts, of course I have not said that, so put that aside. They can disagree; it's that Parliament doesn't have the authority to put in place a law that is unconstitutional.

The other thing I would say on the evidence is, look to Carter, look to Truchon. They reviewed all of that evidence that has been talked about as if we have different views of it.

Don't take my view and don't take Professor Lemmens'. Look at the court proceedings where these very witnesses, the very authors of all of these papers, were actually in front of Justice Baudouin and in front of Justice Smith. She heard them, and they were tested. They both made judgments as to reliability and also, really importantly, the relevance to Canada. These are different countries, jurisdictions and systems, and they were both saying that we have to look to Canada and assess it all in our context.

Go to the primary source and look at the judgments.

The Joint Chair (Hon. Hedy Fry): Thank you very much to both witnesses, Professor Lemmens and Professor Downie.

We said we would leave so that we have 10 minutes to vote. We are now coming up to those 10 minutes. We're going to have bells coming up again very, very soon, so I think it may well be that we will have little time to come to our second hour.

To the two clerks, I am very sorry that we have witnesses lined up to speak, but this is the nature of the beast at the moment with votes.

I want to thank the witnesses for coming. I want to thank everyone for being respectful with their questions, and I want to say that I think this meeting should now be adjourned. Thank you very much.

Hon. Kerry-Lynne Findlay: On a point of order, Madam Chair, I know that we have to go to votes now, but do we know for sure that we have other votes that would interfere? Should we not be suspending and seeing if we can come back?

The Joint Chair (Hon. Hedy Fry): I am told by the whips' offices that there is going to be another set of bells coming up very soon. I think it's at eight o'clock that we will have bells. That means that's going to be another set of votes, and we just won't have the time....

I am so sorry. I would love to continue, but resources have to begin again. People have been waiting for an 8:30 end to committee.

I am so sorry, Ms. Findlay. I would love to continue with this.

I want to thank you all again.

I think we may have to talk to each other soon, because we're not going to be having another meeting. We may have to contact each other with regard to the decisions we made on other issues.

Thank you very much.

Goodbye, everybody.

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