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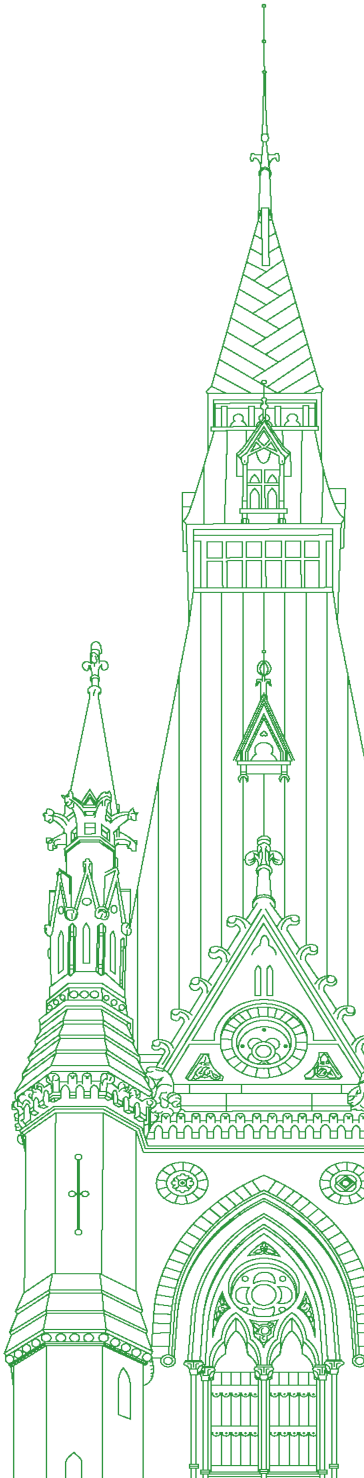

Co-Chairs:
The Honourable Marc GarneauThe Honourable Yonah Martin

Special Joint Committee on Medical Assistance in Dying

Monday, May 9, 2022

● (1835)

[*English*]

The Joint Chair (Hon. Yonah Martin, Senator, British Columbia, C): I call this meeting to order.

[*Translation*]

Good evening and welcome, everyone.

[*English*]

At this time, I will call on Mr. Cooper.

Mr. Michael Cooper (St. Albert—Edmonton, CPC): Thank you, Madam Chair.

I would like to move a motion that I have put on notice. It reads:

> That, the committee dedicate six hours to study the effectiveness, compliance, and enforceability of the legislated safeguards for Medical Assistance in Dying in Canada under both the C-14 and C-7 regimes.

That is the motion. I believe it is important that a review of the existing safeguards and instances of possible abuse and coercion be done by the committee. I would note that pursuant to Bill C-14, there was to be a retrospective review of the provisions in Bill C-14. That review never took place.

There have been a number of well-publicized instances of potential abuse, including recently. A 51-year-old London, Ontario, woman accessed medical assistance in dying after she could not find adequate housing—

The Joint Chair (Hon. Yonah Martin): Mr. Cooper, I'm sorry to interrupt you. In the interest of time, would you be agreeable to my asking the members to adjourn this for today and take it up next week in a dedicated time in next Monday's meeting?

Mr. Michael Cooper: I would be.

The Joint Chair (Hon. Yonah Martin): Is that agreeable to everyone?

Some hon. members: Agreed.

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

Go ahead, Mr. Thériault.

[*Translation*]

Mr. Luc Thériault (Montcalm, BQ): *Madam Chair, I would like us to discuss the following motion, notice of which I gave last week:*

> That, given the importance of the Special Committee on Physician-Assisted Dying's work with regard to the provisions of the Criminal Code and the application thereof, the Committee allocate time as follows to hear witness testimony for each of the components of this study:
>
> a) 12 hours for testimony related to mature minors;
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> b) 12 hours for testimony related to advance requests;
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> c) 12 hours for testimony related to mental health;
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> d) 8 hours for testimony related to palliative care; and
>
> e) 5 hours for testimony related to persons with disabilities;
>
> it being understood that the time already allocated to hear from witnesses at the Committee meetings of April 25 and 28 is taken into account when calculating the number of hours allocated per component.

I would note that it's not the chronology of the components that's important but rather the number of hours.

Madam Chair, it's also understood that, in organizing our work plan, we will have to take into account what the House has recently adopted. That, moreover, is the purpose of this motion. I would note that the committee will be required to table an interim report no later than June 23 on the issue of mental illness as the sole medical condition for requesting medical assistance in dying.

And that's that.

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

[*English*]

Are you also agreeable that we adjourn this discussion until next Monday?

[*Translation*]

Mr. Luc Thériault: That's fine with me, Madam Chair, provided the organization of parliamentary business at the end of the session and the extended sitting hours don't force us to cancel next Monday's meeting or to sacrifice the committee. I want to inform committee members that should such a situation arise next Monday, I'd be upset if the parties decided that the committee wouldn't sit or that it would be sacrificed.

That's my only worry. Otherwise, I agree to adjourn the discussion until next Monday.

[*English*]

The Joint Chair (Hon. Yonah Martin): Is it agreeable to everyone to adjourn the discussion until next Monday?

Some hon. members: Agreed.

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

[*Translation*]

With that, I would like once again to welcome the members of the committee, the witnesses and members of the public who are following this meeting of the Special Joint Committee on Medical Assistance in Dying.

[*English*]

I am Senator Yonah Martin, and I am the Senate's joint chair of this committee.

I'm joined by the Honourable Marc Garneau, the House of Commons' joint chair.

[*Translation*]

Today we continue our planned review of the provisions of the Criminal Code relating to medical assistance in dying and their application.

[*English*]

The Board of Internal Economy requires that committees adhere to the health protocols, which are in effect until June 23, 2022. As joint chairs, we will enforce these measures, and we thank everyone for their co-operation.

I'd like to remind members and witnesses to keep their microphones muted unless recognized by name by the joint chair.

As a reminder, all comments should be addressed through the joint chairs. When speaking, please speak slowly and clearly.

Interpretation in this video conference will work as it does in an in-person committee meeting. You have the choice, at the bottom of your screen, of either “floor”, “English” or “French”.

With that, I'd like to welcome all of our witnesses.

For the first panel, we have, as individuals, Louise Bernier, professor, faculty of law, Université de Sherbrooke, and Trudo Lemmens, professor, Scholl chair, health law and policy, faculty of law, University of Toronto.

[*Translation*]

We also have Ms. Danielle Chalifoux, lawyer and chair of the Institut de planification des soins du Québec.

[*English*]

Each of our witnesses will have five minutes, starting with Ms. Bernier.

[*Translation*]

Ms. Louise Bernier (Professor, Faculty of Law, Université de Sherbrooke, As an Individual): Good evening. I am delighted to be with you today as part of your study on advance requests for medical assistance in dying, although I am personally more concerned with requests that are made following a diagnosis of neurocognitive disorder.

Today I will be providing you with some food for thought in three main areas: first, support in making advance decisions; second, implementing MAiD; and, third, the long-term effects of this societal decision more generally.

I will begin with support in making advance decisions.

In my research work, I have realized how important it is not to be sparing with this type of support. Since advance consent is always imperfect, we really must reflect on how we plan to support patients in their process of consenting to end-of-life care, or final care. If we go ahead and allow advance requests for medical assistance in dying, it will be very important that patients be supported by health professionals. We must develop mechanisms to ensure that their choice is not made without medical expertise, given the complex nature of these conditions and the various possible stages and scenarios.

In Quebec, we have a system of advance medical directives on which I have done a considerable amount of work in recent years. To respect individual autonomy and create a tool that's flexible and easy to use, we have come up with a very simple solution: a form with boxes to tick. We even assumed that patients had gathered information before signing it. If we decide to allow advance requests for medical assistance in dying, we will definitely have to do things differently. There has been very little uptake of our advance medical directives system, and that may be one of the reasons why.

What I'm imagining is a flexible tool that would help people establish priorities and provide a reference point when they become incapable. They should also be able to ask questions, to be supported and to plan, together with other professionals, how all that will fit in with follow-up care. People must not be left to their own devices. There is broad acceptance in Canada and Quebec of the idea of being able to make such an advance decision on one's own, but, from what I have observed from my reading and work, we also have a duty of support.

There is also the idea of letting people change their minds. I will even go so far as to say that consent should be an ongoing process, by which I mean that people must reaffirm their informed consent to this care as their condition evolves, relying on the experiential knowledge they have acquired.

The second part of my presentation concerns the importance of reflecting on the implementation of this choice, which is often described as an individual choice rooted in individual autonomy and self-determination. I obviously don't question this, but we also cannot disregard the fact that this choice, once the person has become incapable, will be implemented by third parties, mainly health professionals, who are also governed by professional, ethical and legal obligations.

You are obviously aware of the assessment that these professionals are required to conduct under the act. Currently, for example, there is the criterion of suffering, which always resurfaces. For access to care to be granted, it must be established that the person is experiencing persistent and intolerable suffering. How is that suffering assessed? I don't have the answer. Will we allow individuals to determine in advance what suffering is for them? Will we request a contemporaneous assessment of that suffering? What will we do if there are no factors indicating whether the incapable person is suffering or not?

What I'm getting at is that we must provide the caregivers and health professionals who execute the decision with markers and tools. We want to prevent them from being troubled by existential questions and wondering whether they have correctly interpreted the situation. We also want to prevent them from suffering in the process.

● (1840)

There will also be repercussions for family members, who, whether we like it or not, will also play a central role in these decisions. They won't be making the decisions, but they will be involved. What role will be assign them? Do we want to give them a role that's more…

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

Ms. Louise Bernier: Is my time already up, Madam Chair?

The Joint Chair (Hon. Yonah Martin): Yes, the five minutes are up.

Ms. Louise Bernier: I had something else to add. May I finish what I was saying?

[*English*]

The Joint Chair (Hon. Yonah Martin): Yes, just very quickly. Thank you.

[*Translation*]

Ms. Louise Bernier: All right.

I would just like to say one thing about my last point, which concerns the societal choices associated with medical assistance in dying. We must ensure that we continue providing care. I'll come back to this later, and I would ask you to remind me to do so.

Thank you.

● (1845)

[*English*]

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

I'll try to give a 30-second warning as well.

Next we have Mr. Trudo Lemmens for five minutes, please.

Dr. Trudo Lemmens (Professor, Scholl Chair, Health Law and Policy, Faculty of Law, University of Toronto, As an Individual): I thank the committee for the invitation.

I was, as professor of law and bioethics, a member of the Council of Canadian Academies' expert panel on advance requests for MAID. I have studied MAID and euthanasia law and practice, particularly also in the Belgian and Dutch regimes.

As others, I come to this with previous experience. I think of my late mother, who lived in Belgium, where euthanasia based on an advance request is only possible when a person is no longer conscious. Belgium has relatively good elder care, and my mother had some reassurances that she would be treated with the care our elders with dementia deserve and their inherent dignity requires. I think of my Montreal father-in-law, who had a supportive spouse and the means to receive good quality home care.

Many Canadians, however, face he prospect of being warehoused in substandard long-term care homes. We already see how lack of resources and quality care lead persons who are not dying to request MAID. It is in this context that AR for MAID is put forward as a solution to what is referred to as a loss of dignity—yet, we know that quality care is possible and can preserve dignity.

If some recent recommendations are followed, health care providers would need to introduce MAID when informing a patient of a devastating diagnosis of, say, early Alzheimer's. This ignores, in my view, the dynamics of doctor-patient relations and the pressure that can result from professionals suggesting that medicalized death is a solution in a context where lack of social and good elder care support are already undermining consent.

ARs for MAID further raise insurmountable ethical and human rights concerns. We should reconsider them and, in my view, not expand them further. The concerns they raise are reflected in this: Belgium only allows MAID based on advance requests when persons are permanently unconscious, to avoid euthanizing people who still enjoy life and may resist. The Netherlands originally had difficulty with MAID based on advance requests, since they considered it impossible to defend it on the basis that persons “suffer unbearably” if they could no longer confirm this. It now has permitted it for persons, even when they appear to resist.

Neither regime involves explicit, contemporary consent, arguably constitutionally required if we take the Supreme Court's emphasis on “clear consent” in Carter v. Canada seriously. Allowing AR for MAID reflects the idea that prior wishes of patients who cannot fully appreciate what future illness will bring have priority over current interests; that this can be done by procedures that give third persons clarity about levels of suffering and patients' real wishes; and that there are no serious implications for family members, health care providers, other disabled persons and society at large. AR for MAID is, in this view, a question of management.

The Council of Canadian Academies' expert report shows that there is no evidence that procedural solutions can easily address the legal and ethical concerns. Even its discussion of communication tools to reduce uncertainty shows that these solutions are theoretical and speculative.

The International Convention on the Rights of Persons with Disabilities explicitly recognizes in its article 12 the inherent legal capacity of persons with cognitive disabilities. This implies a duty to enable expressions of current interest.

Evidence from the Netherlands, the only jurisdiction that allows euthanasia of persons with advanced dementia who are still conscious, shows what this means. It inevitably involves third party consent and evaluation of the person's suffering. It usually involves surreptitious medicating of patients to suppress resistance and then actively ending life. Contrary to withholding treatment in other health care contexts, it involves an active invasion of a person's bodily integrity. Surreptitious medicating and suppressing resistance violate ethical norms and run counter to the duty to enable an expression of current interests of cognitively disabled persons, which the international convention requires. It moves us into involuntary ending of life. It expresses in law also the view that life with cognitive disability involves loss of dignity.

I urge the committee to read a recent article by Belgian and Dutch experts, who argue that Belgium should avoid the Dutch approach. Belgium legalized euthanasia in 2002. Twenty years later, and informed by the practice in the neighbouring country, it still hasn't expanded its AR regime for MAID. Our current AR regime for MAID already goes beyond Belgian law, while our social and health care support is below the OECD average.

● (1850)

We should listen to experts who tell us, based on the Dutch experience they've studied—and these are not people who are against legalized MAID—that ARs for MAID create insurmountable ethical and legal concerns—

The Joint Chair (Hon. Yonah Martin): Please finish up, Mr. Lemmens.

Dr. Trudo Lemmens: Yes.

We should prioritize health care and social support that promotes the human rights of all, including those with cognitive disabilities.

I thank you for my time.

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

Finally, we'll have Danielle Chalifoux.

[*Translation*]

Ms. Danielle Chalifoux (Lawyer and Chair, Institut de planification des soins du Québec): Senators and members, thank you for inviting me.

I have been a member of the Barreau du Québec since 1985 and, since 2010, chair of the Institut de planification des soins du Québec, which is particularly interested in the seniors' rights and medical assistance in dying.

I have published many articles on those topics and have sat on numerous expert panels and government and parliamentary commissions.

I have also conducted studies on nursing care and practice, mainly in CHSLDs and palliative care homes, which has helped me understand the issues in a more practical way.

Given the time allotted me, my comments will focus solely on potential statutory amendments respecting advance requests for medical assistance in dying.

First of all, I would emphasize that rescinding the reasonably foreseeable natural death criterion has resulted in a considerable increase in the number of persons able to access medical assistance in dying. For those with cognitive disorders, for example, it is now sufficient for their grievous and irremediable health condition to be accompanied by an advanced state of irreversible decline in capacity and suffering that they obviously consider intolerable, provided they are still sufficiently capable.

I would note that the Canadian Association of MAiD Assessors and Providers, which really is the authority in this field in Canada, considers that the imminent loss of capacity associated with neurocognitive disorders must be considered as an advanced state of irreversible decline in capacity. When the loss of capacity is anticipated in the near future, these persons may then request and receive medical assistance in dying contemporaneously.

In addition to this option, it would also be possible to make an advance request for medical assistance in dying. These individuals would thus have two options.

Now I would like to draw your attention to the fact that some people recommend granting medical assistance in dying solely to persons who, before making a request, have received a diagnosis of neurocognitive degenerative disorder.

If Parliament adopted such a restriction, that would mean that victims of sudden and unforeseeable impairment that may result in a loss of capacity, such as stroke and severe cranial trauma, would be excluded as they clearly would not previously have obtained a diagnosis. The Institut de planification des soins du Québec believes that the adoption of such a restriction would be neither legitimate nor lawful.

This restriction would be illegitimate because it would run counter to the opinion of a very large majority of citizens. In the public consultation that the Quebec government recently conducted in the course of its work, 91.8% of respondents were in favour of advance requests for medical assistance in dying in the event of sudden and unforeseeable incidents resulting in a loss of capacity.

This restriction would also be unlawful in our view because it would contravene section 1 of the Canadian Charter of Rights and Freedoms and at least two of the tests established in the Oakes judgment. It would contravene Parliament's obligation to impair rights as little as possible because appropriate and far less draconian safeguards could be adopted. It would also contravene the proportionality test as the benefits would be more operational, but the deleterious effects would amount to a negation of recognized rights, both the right to self-determination of persons and the right to medical assistance in dying.

In conclusion, if Parliament adopted such a restriction preventing medical assistance in dying from being granted to persons who have obtained a prior diagnosis, all victims of a sudden and unforeseen impairment would be deprived of their rights. Thus, the first class of persons that we discussed earlier would have two options, to make a contemporaneous or an advance request for medical assistance in dying, whereas persons unable to make an advance request before obtaining a diagnosis would have none.

● (1855)

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

Ms. Danielle Chalifoux: I just have one sentence left.

I believe that this requirement could be struck down, somewhat as was the case of the requirement of reasonably foreseeable natural death in the Truchon and Gladu case.

Thank you for your attention.

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

[*English*]

I will turn this over to our co-chair for the first round of questions for MPs and for senators.

The Joint Chair (Hon. Marc Garneau (Notre-Dame-de-Grâce—Westmount, Lib.)): Thank you very much, Senator Martin.

[*Translation*]

We will now begin the first round of questions, during which each speaker will have five minutes.

Ms. Viens, go ahead for five minutes.

Mrs. Dominique Vien (Bellechasse—Les Etchemins—Lévis, CPC): Thank you, Mr. Chair and Madam Chair.

I want to thank our guests for being with us this evening.

Ms. Bernier, you were on a roll a little earlier on the topic of the third part of your presentation. So I want to let you finish what you were saying. You were discussing the importance of continuing to provide care. I'll give you the floor for a few seconds, after which I'll ask you my questions.

Ms. Louise Bernier: Thank you very much. I'm grateful for that. This will allow me to explain my final point and round out my remarks.

If we, as a society, choose to expand access to medical assistance in dying, we must not downplay the impact that could have on the more social aspect of the autonomy that's exercised.

We must consider the effect that an expansion of access to medical assistance in dying would have on social perceptions of illness. No one who receives a diagnosis of neurocognitive degenerative disease should feel that he or she is expected to request medical assistance in dying now that it's being offered. We must also continue to invest in providing parallel care, as Mr. Lemmens said, to ensure that those who make a different choice continue to receive care, that there is no interruption of care and that there is no therapeutic abandonment.

That's the point I wanted to make. I'm very pleased to have had the opportunity to do so because it was really important for me to discuss the societal aspect of this issue. It should not become the ideal option, and we must not abandon people who don't make that choice.

Mrs. Dominique Vien: Ms. Bernier, are you completely comfortable with advance requests?

Ms. Louise Bernier: The more I examine the issue, the less certain I actually am. It's my occupation, so…

Mrs. Dominique Vien: That's what I sensed as I listened to your presentation.

Ms. Louise Bernier: Actually, it's not that I'm uncomfortable with advance requests; I'm more uncomfortable if there isn't an appropriate mechanism. The fact remains that an advance decision isn't made on the spot; it's a decision that people make, as best they can, in advance of a situation, based on the knowledge at their disposal.

I don't think I'm qualified to judge whether its appropriate to expand access to medical assistance in dying. If that's where we now stand, and a large segment of society thinks it's a good idea, that's fine. However, I think there'll have to be a lot of guidelines and support measures.

My studies focus on consent, individual autonomy and relational autonomy. You have to understand that decisions aren't made in isolation. The decision or wish to receive care, for example, is part of a dynamic that includes caregivers and family members.

Mrs. Dominique Vien: Earlier, in the second part of your presentation, you said it was extremely important to provide adequate support and not to leave the people to their own devices.

Have you witnessed or heard of any deviations from that rule? Has anyone not been informed of all aspects of the process?

● (1900)

Ms. Louise Bernier: Deviations necessarily occur. It's more that I see a lot of major problems in our advance medical directives system these days. People are left to their own devices. Patients are told that it's easy, that all they have to do is sign, and it's assumed that they're informed.

I think this is a golden opportunity to establish a mechanism, and we really need to seize it.

Mrs. Dominique Vien: I see.

Thank you very much, Ms. Bernier.

Good evening, Ms. Chalifoux. Thank you for being with us this evening.

You say it shouldn't be necessary to get a diagnosis beforehand. You laid out your arguments on that point.

However, I'm interested in what's happened in Quebec, and unless I'm mistaken, Ms. Chalifoux, Quebec hasn't gone that far. We're waiting for the party in power to table the bill once the committee has done its work. At any event, we aren't going as far as you and other individuals suggest. We're saying yes to advance requests in cases of neurodegenerative conditions, but if, and only if, a diagnosis has been established.

Ms. Danielle Chalifoux: That's correct.

I'd like to tell you from the outset that I share Ms. Bernier's [x] opinion on support. Having worked in the nursing field and seen some of what happens in palliative care homes, in particular, I can't overemphasize how important the quality of free and informed consent is with regard to advance requests. Terms and conditions must absolutely be established so that, when people consider making an advance request, they can get references and discuss the matter. It's not enough just to complete a form. People really need to discuss it so they can see all the ins and outs and carefully reflect on the matter.

I absolutely share that opinion.

The Joint Chair (Hon. Marc Garneau): Thank you, Ms. Chalifoux

I now give the floor to Mr. Arseneault for five minutes.

Mr. René Arseneault (Madawaska—Restigouche, Lib.): Thank you, Mr. Chair.

Ms. Chalifoux, since my colleague Ms. Viens' questions are very interesting, I'm going to give you an opportunity to provide some more details.

Ms. Danielle Chalifoux: We still don't really know the scope of the bill that will emerge from the work of the National Assembly committee charged with examining the evolution of medical assistance in dying. It will probably tend to be more restrictive such that only individuals who have received a prior diagnosis will be able to request such assistance.

Mr. René Arseneault: So you're saying you must have a diagnosis even before you can make an advance request.

Ms. Danielle Chalifoux: I think that's what they're getting ready to do in Quebec. However, I have to say I completely disagree.

Mr. René Arseneault: In a few words, what form do you think the preparation process should take to ensure that people who request medical assistance in dying truly make an informed decision?

Ms. Danielle Chalifoux: When I appeared before the select committee that was studying the evolution of the Act respecting end-of-life care, I suggested that some sort of agency be established to do all the work involved in informing and training the people concerned, somewhat as what the Canadian Association of MAiD Assessors and Providers does on the anglophone side. I think we should have something like that.

Mr. René Arseneault: Ms. Bernier, I want to continue along those lines with you.

Earlier you said we need to ensure the process is overseen by health professionals. Personally, I come from a rural region. People in urban areas have access to all kinds of professionals, whereas you may have to wait a year and a half to see one of those professionals in a rural region. So this really troubles me.

I'd like to ensure that people in the rural regions, the remote or northern regions, can get the same services as people in urban areas. So I'd like you to tell me exactly what you mean when you refer to professionals.

Ms. Louise Bernier: There are actually various categories of professionals. As Ms. Chalifoux said, they may be people who've been trained in various health fields and have received some accreditation, although I really think that should become a kind of health care standard. These people have received a diagnosis and will therefore have follow-up…

● (1905)

Mr. René Arseneault: Pardon me for interrupting. So a nurse practitioner trained for that purpose would do. Is that correct?

Ms. Louise Bernier: Absolutely. There has to be follow-up. There has to be a way to transmit information. I also think it should be done continuously, as the condition evolves, not just one final time.

Mr. René Arseneault: When you refer to something resembling a standard, that would be at the national level, wouldn't it?

Ms. Louise Bernier: I think it could be determined by the professional associations. Certain aspects would also have to be determined: if this becomes a protected act, is it a paid act, and how does that have to be organized? This is a bit beyond my field of expertise, but I think this is a really good opportunity to establish standards.

Mr. René Arseneault: A professional who came to talk to us about this issue last week told us he thought advance requests should be reviewed every five years.

What you think about that?

Ms. Louise Bernier: I think that could be done depending on how the condition progresses. It could be every five years or a little less than that if the condition evolves very quickly. There may not be any absolute rule, but, yes, it could definitely be done at least every five years.

I think it would be wise to provide for requests to be reviewed because circumstances change. We have a lot of data on experiential knowledge and on the way people's perceptions can change following an announcement because they ultimately grow accustomed to certain things. People may not change their minds in the end, but they must have an opportunity to review certain choices.

Mr. René Arseneault: Do I have any time left, Mr. Chair?

The Joint Chair (Hon. Marc Garneau): You have one minute left.

Mr. René Arseneault: Mr. Lemmens, I'm not sure I understood your remarks so I'd like a few points clarified. You aren't in favour of advance requests, and you say we must be cautious.

How cautious do we need to be? In other words, do you mean we have to be cautious to the point of preventing advance requests? Is that in fact what you're saying?

Dr. Trudo Lemmens: Yes. I'd say the experience of the Netherlands and Belgium shows that advance requests for medical assistance in dying create insurmountable ethical and legal concerns. Furthermore, the practice in the Netherlands sometimes involves the involuntary administration of medication to anaesthetize patients in order to complete the euthanasia procedure or…

Mr. René Arseneault: I apologize for interrupting, Mr. Lemmens, but I have only 20 seconds left.

Regardless of what's done elsewhere—we are, of course, in Canada, and we're going to develop our own bill—we believe it's impossible to introduce safeguards that will protect someone deemed to be of sound mind who makes an advance request for medical assistance in dying.

Is that correct?

Dr. Trudo Lemmens: Yes. It creates more problems. There are other approaches to providing assistance to those persons.

Mr. René Arseneault: For whom does it create problems?

Dr. Trudo Lemmens: For…

The Joint Chair (Hon. Marc Garneau): Thank you.

Mr. Thériault, you have the floor for five minutes.

Mr. Luc Thériault: Thank you, Mr. Chair.

Ms. Chalifoux and Ms. Bernier, in Quebec, we have what are called advance medical directives. They aren't yet widely known, and they very often apply to specific situations. For example, one can consider the desired level of care when a relative enters a CHSLD, which is a long-term care facility. Advance medical directives cover discontinuation of treatment, refusal of treatment, level of care, reanimation and so on, and that's not well known.

Shouldn't we develop an entirely separate process for advance requests for medical assistance in dying, as some witnesses have proposed? That would apply to neurodegenerative disease cases, where the stages of development are predictable and there's an established process and an entire team following the patient right up to the medical-assistance-in-dying stage.

Shouldn't the cases you refer to, strokes, aneurysms and so on, be covered by advance medical directives?

Conceptually speaking, wouldn't it be better to distinguish between the two mechanisms so we can move forward cautiously, as circumstances dictate?

● (1910)

Ms. Louise Bernier: Who's that question for?

The Joint Chair (Hon. Marc Garneau): Ms. Bernier, you may start answering the question.

Mr. Luc Thériault: First, I'd like to hear ^{x} Ms. Chalifoux' comments because I wanted to make a connection with Quebec.

Ms. Danielle Chalifoux: I see two aspects to your remarks. I find your questions very interesting.

First, the advance medical directives that we have in Quebec wouldn't be applicable to medical assistance in dying. They're binding, by which I mean they are mandatory, and they apply to situations that don't call for extremely long and extensive reflection. Consequently, they're easier to apply.

Mr. Luc Thériault: That's correct.

Ms. Danielle Chalifoux: That's why they've been well received.

For example, consider a man who becomes incapable following a stroke and is in the same situation as a person suffering from a neurocognitive disorder, by which I mean that his condition is grievous and incurable, that he is experiencing what he deems intolerable suffering and so on. That case must definitely be distinguished from those that are the subject of the advance medical directives provided for under Quebec's Act respecting end-of-life care. I think those are two completely different things.

Mr. Luc Thériault: So you agree with me that there's a necessary distinction.

Ms. Danielle Chalifoux: Yes.

Mr. Luc Thériault: However, you don't agree that the medical situation you referred to falls under advance medical directives, even if…

Ms. Danielle Chalifoux: No.

Mr. Luc Thériault: All right, I understand that.

However, you do agree that a distinction must be drawn between the two regimes because they don't concern the same thing.

Ms. Danielle Chalifoux: That's correct. They aren't the same thing.

Mr. Luc Thériault: As regards support and the process, Ms. Bernier, we haven't been sitting for long, but we've heard a great deal.

We've discussed a distinct official form and a diagnosis. We said the request should be repeated and be made mandatory. We said that patients should be able to revoke their request at any time and that objective criteria had to be established. We talked about designating a representative who would decide on the moment but who would communicate with the attending team to ask them to determine whether the patient had passed the tolerable threshold.

Don't these safeguards amount to reasonable support in the circumstances?

Doesn't this calm your fears about potential deviations?

Ms. Louise Bernier: Thank you for that question, which is very interesting.

I have a lot to tell you, but I'll try to summarize my comments.

I've extensively studied the advance medical directives regime, and, as you know, very few people have had access to it. We're talking about slightly more than 100,000 persons in Quebec, so it isn't an extensively used regime.

I don't share ^{x} Ms. Chalifoux' view. I think advance medical directives do cover strokes. We should separate that and stick to diagnoses of neurocognitive disorders.

As for support, that's a very interesting question, but I don't think we can do without a discussion beforehand. There's an implementation problem. A read flag is raised because of what was said, but there was no discussion.

According to some recent studies conducted in 2022, the discussion is far more important for patients than the form. Consequently, it's important to discuss various scenarios with them and to ascertain their values. I think it's important to state in advance that the process won't be limited to the form and that the basis of the decision will be explained.

It's also important that the family be present.

I really view this support as being divided into two parts.

The Joint Chair (Hon. Marc Garneau): I would ask you please to conclude your remarks soon, Ms. Bernier.

Ms. Louise Bernier: There are the measures, and there's the dialogue. I think that has to be preserved.

Mr. Luc Thériault: Are you talking about the family or a proxy?

[*English*]

The Joint Chair (Hon. Marc Garneau): Thank you very much, Monsieur Thériault.

It's now Mr. MacGregor's turn. You have five minutes.

Mr. Alistair MacGregor (Cowichan—Malahat—Langford, NDP): Thank you very much, Mr. Co-Chair.

It's quite obvious, when you look at the status of health care in Canada, that many groups simply do not have access to equitable care. There are very real concerns for many communities out there about the conversations we're having around this table and the direction that this law could potentially be taking.

Professor Bernier, I'll start with you.

On the subject of informed consent in relation to the concept of advanced requests, we noticed that a lot of people have a fear of being a burden on their families. Given the state of long-term care in Canada, they also have a fear of losing their agency. They look at people who may live with disabilities. They fear being put into that kind of life.

In this conversation, we're dealing with very weighty subject matter. I mean, how on earth are we going to address this committee's mandate, if we're not...? It seems like we're putting the cart before the horse if we're not dealing with those larger societal issues, these bigger and broader topics of equitable care being unavailable to so many under-represented groups.

If we're not dealing with that, how are we proceeding on this? Do you have any thoughts on that?

● (1915)

[*Translation*]

Ms. Louise Bernier: I don't think they are mutually exclusive. If we want the debate on extending medical assistance in dying to include advanced directives, it's altogether possible that we would see people choosing that option while fully aware that they've made that decision because they don't want to be caught in a situation that's not equitable.

As for the relational autonomy I was speaking about earlier, you're right to mention that our decisions are rooted in a context that is both cultural and familial. We are influenced by a lot of factors. It is in fact quite possible that one's decision about opting for medical assistance in dying is, as Mr. Lemmens said, based on the perception we have of available care.

Someone might not want to feel diminished, and it's a choice they make. I'm not questioning that. What I'm saying is that if we go in that direction, then it shouldn't be become the only option. I spoke earlier about therapeutic abandonment. I believe that it's really important to continue to expend a lot of energy and resources on quality care for people.

I don't know whether that answers your question. Don't hesitate to get back to me as needed.

[*English*]

Mr. Alistair MacGregor: No, no. Thank you very much for that.

Professor Lemmens, maybe I'll turn to you.

I was taking notes as you were speaking. You were speaking about the problem of procedural tools and their inability to fix these broader ethical issues.

Do you want to take some time to expand on that? I think that's a very real challenge that we have. It's the crux of the matter before us as a committee.

Dr. Trudo Lemmens: I would first of all say that the procedural tools you find in the Council of Canadian Academies' report focus on issues of communication, even at the level of guaranteeing that persons are respected in their future choices when they are no longer the same person or have the same interests.

As Professor Bernier has shown—and also the work with her colleague Professor Régis, at the Université de Montréal—in the context of advance requests, we know already it is very hard to predict in advance what we will think, what will happen and what kind of interests we will have. That's one issue that is already not guaranteed by the procedural tools.

The procedural tools certainly do not address broader societal concerns, such as the fact that we're crossing the line into allowing third parties to decide whether a person is now suffering intolerably and whether the person's life can be ended. We're crossing a line, which impacts also on our perception of cognitive disabilities more generally. If we do it for people who, before becoming cognitively disabled, say that they will want to die because they will lose dignity, what do we say to people who currently have cognitive disability and have not made that choice?

We're crossing a line into a practice that undermines a fundamental commitment to allowing persons with cognitive disability to be treated with respect and dignity and to be involved in the decision-making. The international Convention on the Rights of Persons with Disabilities emphasizes that. It's not the case that when someone has cognitive decline, you can say, “Oh, in the past you made this decision and now we will ignore your current identity and interests and give you surreptitious medication against your explicit consent and then end your life.” These issues cannot be solved by procedural means.

● (1920)

The Joint Chair (Hon. Marc Garneau): Thank you very much.

We'll now go to the senators. These are three-minute rounds.

We'll begin with Senator Kutcher.

Senator Kutcher, you have three minutes.

Hon. Stan Kutcher (Senator, Nova Scotia, ISG): Thank you very much, Mr. Chair.

I have two questions for Ms. Chalifoux.

The first one is this: Do you think the fact that concerns have been raised about how advance requests are managed in some countries is a valid reason for advance requests to be prohibited in Canada, or do you think that Canada can set up its own system of humane and comprehensive safeguards for advance requests, which may differ from that in other countries?

Second, if that's the case, who should develop these safeguards and how should they be implemented? Would a national standards and certified training program for MAID providers be a useful tool in addressing this issue?

[*Translation*]

Ms. Danielle Chalifoux: In response to your first question, there are indeed examples of these practices elsewhere. The Netherlands introduced advanced medical directives just over 20 years ago. That's certainly long enough for them to have acquired some expertise.

I simply want to underscore the fact that in Quebec, an expert committee of which I am a member submitted to the government a way of proceeding with all kinds of guidelines for the application and implementation of these advanced medical directives. We went into a great deal of detail, and I believe that it is an original body of work because we didn't see anything of this kind elsewhere. It truly met the requirements for the implementation of medical assistance in dying requests.

I think that your second question was mainly about safeguards. It's definitely more complicated to assess the situation for instances of advanced medical directives than it is for contemporary requests.

I am somewhat in agreement with what Ms. Bernier said when she spoke about the importance of preparing a profile of values and to think about personal choices. People need to be really aware of what they want to do. If we want to protect the right to self-determination in connection with requests for medical assistance in dying, then we need to provide all the information needed to give people the best possible conditions for them to make a request that is the outcome of free and informed consent.

The Joint Chair (Hon. Marc Garneau): Thank you very much.

I'm now going to Senator Mégie.

Senator Mégie, you have the floor for three minutes.

Hon. Marie-Françoise Mégie (Senator, Quebec (Rougemont), ISG): Thank you, Mr. Chair.

I'd like to thank the witnesses for being here with us today.

Ms. Chalifoux, I know that the Institut de planification des soins du Québec, in a brief to the Council of Canadian Academies concerning advance medical directives, had listed five or six safeguards.

Could you cite them fully and send us the document, even though it goes back to 2017?

We'd like to see whether the Institut has changed its mind since then. It would be helpful if we had the document.

Thank you.

Ms. Danielle Chalifoux: I'd be happy to send it along. The document is already several years old, and I believe the views of the Institut de planification des soins du Québec may have shifted somewhat since then. I don't have all the conditions that were mentioned with me, but basically, with respect to advance requests, it's to support people when they are making the request to ensure that there was free and informed consent.

The other crucial moment is when you have to determine whether someone has reached the stage at which they felt the time has come for them to receive medical assistance in dying. It's very important to always show respect for the desires expressed by them. That's why the request for medical assistance in dying has to be detailed. In the request, patients should mention the threshold of suffering required for the moment when they wish to receive medical assistance in dying in accordance with their wishes. The people around them, whether the multidisciplinary medical team, the family or caregivers, would be with the patient, but they are not the ones who should be making the decision. To respect people's right to self-determination, it's very important for the advance request to clearly and precisely state the patient's intentions.

There were certainly other conditions mentioned in the brief as well, but unfortunately, Ms. Mégie, I don't have them in front of me. I'll definitely send you the document.

● (1925)

Hon. Marie-Françoise Mégie: Do I have a few seconds left, Mr. Chair?

The Joint Chair (Hon. Marc Garneau): You have 15 seconds left, Ms. Mégie.

Hon. Marie-Françoise Mégie: Ms. Bernier, I was very pleased to hear your talk about the duty to provide support.

In your opinion, at what point should medical assistance in dying be provided after the advance request is made?

The Joint Chair (Hon. Marc Garneau): Please be brief, Ms. Bernier.

Ms. Louise Bernier: Okay.

It all really depends on the progression of the disease. Ms. Vien asked why I felt ill at ease, and that's why. What's involved is determining the appropriate moment ahead of time, without altogether understanding the course of the disease. There are various possible scenarios, and suffering is one of the factors on which I have trouble taking a position

When a person assesses suffering ahead of time, it's the person in the present who is making a decision about the person of the future. There is abundant scholarly literature on that subject. Has the person undergone a change in identity or not?

When someone does not appear to be suffering, it's difficult to determine the right moment to provide medical assistance in dying legally, while complying with our moral, professional, and ethical obligations as caregivers. The assessment of suffering is therefore something that requires in-depth consideration.

The Joint Chair (Hon. Marc Garneau): Thank you very much.

[*English*]

We'll now to go Senator Wallin.

Senator Wallin, you have three minutes.

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

I would like to make a comment, if I could, Chairs, that over the last few sessions we have heard witnesses so many times using pejorative words and making claims about surreptitious medicating and other things. I think we need to make sure in advance that our witnesses are reminded that their statements should be supported with evidence and documentation if they are going to be meaningful for us here, and they should be qualified to comment on this, because it is our mandate to look at advance requests.

My question is for Danielle Chalifoux.

We talk a lot about safeguards for health care professionals. I think you mentioned that again this evening. I guess my concern is about the safeguards and assurances for the individuals who, being of sound mind, ask, through an advance request, to have MAID when certain conditions are met or when they have reached a certain level of decline.

How can we actually assure them of those safeguards without something like an advance request being expected and recognize that there simply isn't any other way?

[*Translation*]

Ms. Danielle Chalifoux: That, in fact, is exactly what the Institut wants to emphasize. If someone wants to put an end to their suffering when they become incapacitated and meets the conditions for receiving medical assistance in dying, the only way to arrange for that is with an advance request. Once the person is incapacitated, it's too late. They can no longer give their consent. It also becomes impossible to obtain a proxy consent.

The vast majority of people do not want to experience such a situation. People have often said that to me that at my lectures, particularly people with cognitive disorders. Such people have often seen members of their family suffer terribly and lose every ounce of their dignity. They don't want to live through it themselves. It's important to be able to make things easier for them in every possible way.

I know that it's a sensitive issue and that it is not necessarily easy, but conditions are often anything but ideal. I believe that it's definitely possible to take appropriate safeguards that could prevent people from suffering intolerably at the end of life, once they have become incapacitated.

● (1930)

[*English*]

Hon. Pamela Wallin: For anybody who has had any experience with this—a loved one or family member who has gone through this and has suffered through something like dementia or Alzheimer's—it is reasonably foreseeable what the outcome will be. Therefore, it seems we could make that advance request.

[*Translation*]

Ms. Danielle Chalifoux: I fully agree with you, Ms. Wallin.

The Joint Chair (Hon. Marc Garneau): Thank you very much, Ms. Wallin and Ms. Chalifoux.

Senator Dalphond now has the floor.

Hon. Pierre Dalphond (Senator, Quebec (De Lorimier), PSG): Thank you, Mr. Chair.

I'd like to thank the witnesses for their insightful testimony.

Ms. Chalifoux, you said that advance requests should not be restricted to cases of neurocognitive disease because that would exclude all other types of medical problems, such as strokes.

For the former, the assumption is that a person received a diagnosis and is still capable of making a decision, but this decision cannot be reviewed afterwards because the person's capacity to give informed consent will have disappeared. For the latter, a person who has had a stroke or who is suffering from another disease may have made a decision 10 years or even 20 years earlier, and it would be possible to develop a mechanism that would review the circumstances every five years, for example.

What you're really suggesting is introducing different regimes depending on the type of advanced directives.

Is that correct?

Ms. Danielle Chalifoux: Well, the two aspects of the question are not altogether different, because the underlying philosophy for respecting the right to self-determination continues to apply in both. The laws of genetics tell us, for example, that people whose parents have had a stroke also risk having one, and that they are probably worried about it. They say to themselves that they would like to be able to guarantee their right to medical assistance in dying through advanced medical directives.

I believe Mr. Arseneault suggested earlier that there could be an update process to review advance requests every five years, for people to confirm or cancel their decision, if they wish. It's true that this would not exactly be contemporary to the request, if I can use that wording, and it would be up to people to take responsibility for confirming or cancelling their decision. It would amount to a guarantee, or a safeguard, that could facilitate matters.

I'd simply like to mention that in nursing homes and palliative care units I often saw people who had had a stroke and were incapacitated, suffering, and asking to die every day.

I don't see how we could make a distinction between people who have received a diagnosis of a disease about which they can do absolutely nothing, and people who have had a stroke. A stroke happens suddenly, unexpectedly and unforeseeably. These people would be deprived of a right available to others.

Hon. Pierre Dalphond: I understand that it's a different regime, and that it might require different guarantees and safeguards.

Ms. Danielle Chalifoux: Yes, precisely.

Hon. Pierre Dalphond: Thank you.

The Joint Chair (Hon. Marc Garneau): Thank you, Senator Dalphond.

[*English*]

We'll now go to Senator Martin.

Senator Martin, you have three minutes.

The Joint Chair (Hon. Yonah Martin): Thank you, and thank you to all the witnesses. My question is for Professor Lemmens.

I think we have the opportunity to learn from the mistakes of other jurisdictions, if there are such lessons to be learned. Based on your experience studying the Benelux countries, are there concerns with respect to abuse or subtle pressure in the context of an advance request? Can you continue from the answers to some of the questions that other members have asked, and what recommendations or what cautions do you have for us?

● (1935)

Dr. Trudo Lemmens: Thank you for giving me the opportunity to respond, contrary to what Senator Wallin did. She basically questioned my integrity.

I have studied what's happening in the Netherlands, and the practice they described is actually the reason there are more physicians in the Netherlands who are now opposed to medical assistance in dying for persons with dementia than there were before. Contrary to what Maître Chalifoux says, the Netherlands actually did not have the practice of advance requests for MAID in the first years of its legalization. It took many years to start implementing it, and it has become, and remains, more problematic precisely because of the things I described.

Most physicians are now reluctant because of the uncertainty and what it involves. In other words, my message is that we're sending false hope to people that they will actually easily have an implementation of an advance request, because we do not know how the disease will evolve. Four out of 16 cases that the Council of Canadian Academies expert panel studied—so we're not talking about the broad practice that was implemented—involved patients with questionable capacity who received MAID. In those cases, the review committees, which do much more detailed work than we have currently done in Canada, judged that the due care criteria were not respected, so they had questions about the practice.

I'm simply stating the facts, and I find it problematic that a senator questions my integrity when I studied this honestly and with professionalism, and I have come here as an expert to convey what's happening in the Netherlands and what legal scholars and ethics scholars have again recently discussed. This is the dilemma that we face. We will have to surreptitiously medicate people. We will have to deprive them of their ability to express a current wish in order to facilitate the ending of life.

I'm actually very disturbed that a senator makes it difficult for witnesses to talk and to convey the knowledge that they have about practices in other jurisdictions. I find it very inappropriate. We are here in a parliamentary democracy. You invite experts to come and talk about what they know, and you treat them like this. I think it's inappropriate.

I apologize, Mr. Chair and Madam Chair, for saying this here, but I am very disturbed by this.

The Joint Chair (Hon. Marc Garneau): Thank you very much. Unfortunately, this ends our first panel.

[*Translation*]

All that's left for for me to do, Mr. Chalifoux, Professor Lemmens and Mr. Bernier, is to thank you for having been with us this evening, even though it was on only a week's notice. Thank you very much for your testimony and for having answered our questions on a subject which, as you are well aware, is so serious and has such an important impact on people. Your testimony will be included in our report, to be tabled in the fall.

Thank you once more for having come here today.

[*English*]

With that, I will suspend the meeting temporarily as we prepare for the second panel.

Thank you, everyone.

● (1935)

(Pause)

● (1940)

The Joint Chair (Hon. Marc Garneau): Senator Martin, will you be starting the second panel?

The Joint Chair (Hon. Yonah Martin): Yes, I will, Mr. Co-Chair.

For the benefit of our new witnesses, before speaking, please wait until you are recognized by name.

As a reminder, all comments should be addressed through the joint chairs.

When speaking, please speak slowly and clearly. An interpretation in this video conference will work like an in-person committee meeting. You have the choice at the bottom of your screen of “floor”, “English” or “French”. When you are not speaking, please keep your microphone on mute.

With that, I'd like to welcome our witnesses for panel two.

We have, as an individual, Jocelyn Downie, university research professor, faculties of law and medicine, Dalhousie University; Dr. Catherine Ferrier, physician, division of geriatric medicine, McGill University Health Centre; and Dr. Susan MacDonald, associate professor of medicine and family medicine, Memorial University of Newfoundland.

Thank you all for joining us this evening.

We'll begin with opening remarks by Ms. Downie, followed by Dr. Ferrier and Dr. MacDonald.

Ms. Downie, you have five minutes. The floor is yours.

Dr. Jocelyn Downie (University Research Professor, Faculties of Law and Medicine, Dalhousie University, As an Individual): Thank you and good evening.

Thank you for the invitation to appear before you.

My name, as you've heard, is Jocelyn Downie, and I'm a university research professor in the faculties of law and medicine at Dalhousie University.

I have provided written submissions, including relevant references, to the clerk, and in my five minutes I will introduce some key points for your consideration.

I believe that there are three main questions before you on the issue of advance requests for MAID: one, whether to allow them, and if so, two, when to allow them, and three, how to implement them.

First I'll have a word about terminology: Throughout my remarks, I will use the phrase “advance requests” instead of “advance directives”. This is critical to avoid confusion between the relatively new federal regime for MAID, governed by the Criminal Code, and the already well-established provincial/territorial regimes for other health care.

With that, I'll go on to the questions at hand.

Let's start with whether to allow advance requests for MAID. I encourage you to recommend that Parliament do so, for a host of reasons.

First, all of the many expert committees and panels that have studied the issue and had a mandate to make recommendations have recommended this.

Second, public opinion strongly and consistently supports it.

Third, the courts and provinces and territories have said that individuals should, while capable, be able to make refusals of treatment, refusals that are binding after they lose decision-making capacity. What this means is that I can have an advance directive that says when I reach stage 7 of Alzheimer's or have lost capacity due to Huntington's disease, I refuse all food and liquids. The clinicians must respect my directive, so I will die of dehydration and starvation, or, if you change the law, I could have MAID. To deny MAID is both illogical and cruel.

Fourth, Parliament has already made the decision to allow some advance requests for MAID: “Final consent — waiver” and “Advance consent”, introduced through Bill C-7, are two forms of advance request.

Fifth, some persons with dementia already have access to MAID. They are carefully tracked by a provider closely monitoring their diminishing capacity, state of decline in capability, and suffering. After they have met the eligibility criteria for MAID but before they have lost capacity, they can either access MAID through what is known as the “ten minutes to midnight” protocol or sign a final consent waiver, but they must have a provider willing and able to do this, and they may live for years in fear of not getting the timing quite right and not getting MAID.

Sixth, the concerns that you will hear during your process either aren't conceptually coherent, apply to that which we already allow, and/or can be addressed through procedural safeguards. I cannot, in the time allotted, do justice to the complexities of, for example, personal identity, critical interests, precedent autonomy and the paradox of disability, but I can commend to you the analysis in the 2019 report from the Quebec expert panel on the issue of incapacity and medical assistance in dying.

Finally, there has been enough time to consider this legislative reform, from the provincial/territorial expert advisory group in 2015 to the special joint committee of the House and Senate in 2016 to the 2019 Quebec expert panel and to the 2021 Quebec special commission. This has not been rushed—far from it.

Now, let's turn quickly to “when”.

I encourage you to recommend that advance requests should be permitted after diagnosis with a serious and incurable condition.

Finally, let's turn quickly to “how”.

I encourage you to reflect in your recommendations the philosophical justifications for advance requests for access and for protective measures, the values reflected in our existing laws and the realities of clinical practice.

To that end, I encourage you to recommend that the law first require that a valid advance request document spells out both what the person considers will be intolerable suffering as well as objectively assessable conditions for triggering the advance request.

Second, establish what to do if the now incompetent person appears to have changed their mind or does not appear to be suffering—specifically, follow what the person said should happen if they appear to have changed their mind or do not appear to be suffering—and require, as part of the informed consent process, the disclosure that this may happen.

● (1945)

Third, require that the request be renewed on a regular basis so long as the person remains competent.

With that, my time is up. I thank you for your attention and I welcome your comments and questions on anything that I have said or any other matters of interest to you.

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

Next we'll have Dr. Catherine Ferrier.

Dr. Catherine Ferrier (Physician, Division of Geriatric Medicine, McGill University Health Centre, As an Individual): Thank you very much, Madam Chair and Mr. Chair. I'm happy to be here.

I've been a physician in the division of geriatric medicine at the McGill University Health Centre since 1984. My practice is focused on patients with dementia. I'm an expert in decision-making capacity assessment. I see victims of elder abuse. I teach on these topics and testify frequently in court for my patients.

I have cared for and accompanied thousands of people with dementia and their families. My perspective is very different from those who view my patients from an academic or political point of view. I have learned how well people adapt to the changes in their lives wrought by cognitive decline. There are many challenges, not least of which are the ageism, ableism and neglect they face in the health care system.

Despite this, most people do well when measures are put into place to support them and their families. In 38 years, none of my patients or their relatives have ever requested MAID because of a dementia diagnosis.

I've noticed in this debate the assumption that advance written directives are a proven tool that enables autonomy and provides adequate free and informed consent to medical interventions. This is false. For consent to be valid, it must be voluntary. The patient must have the capacity to consent and must be informed. Consent is informed when the patient has received and understands the detailed information in the diagnosis, including any uncertainty, the proposed investigations or treatments, their chances of success, available alternatives and their risks, and the potential consequences of leaving the condition untreated.

Advance consent can never be fully informed.

The 2018 CCA expert panel on MAID by advance requests cited knowledge gaps and a lack of evidence regarding its safety. They reviewed the literature on advance care planning, or ACP, a field that was developed to improve medical decision-making towards the end of life. ACP is not limited to advance directives. In fact, its scope is becoming broader over time, as the limitations of such directives, also called living wills, become evident. Articles published by experts include “Why I don't have a living will”, in 1991; and “Enough: The Failure of the Living Will”, in 2004.

Definitions of ACP refer to a reflection and communication process to ensure goal-concordant care near the end of life for people lacking decisional capacity. Components include discussion of broad life and health care goals and naming a substitute decision-maker.

Of the research reviewed by the CCA panel, very little studied written directives alone. The report mentions no evidence that written directives effected any meaningful outcomes. In one Canadian study, the documented preferences did not match the expressed wishes of the patient 70% of the time.

A 2020 review of 69 studies found no effect of advance care planning on goal-concordant care or quality of life. These results make sense, given the evidence that people predict poorly their quality of life in hypothetical situations. This has been attributed to known cognitive biases, such as projection bias, projection of current preferences onto future situations; focalism, focusing on what gets worse, not what remains positive; and immune neglect, underestimating one's adaptive capacity.

We often see a change in preferences for care as a person adapts to advancing illness. This is true even in dementia, and it is is why we respect the current wishes of incapable patients as long as they are not harmful to the patient.

More and more end-of-life experts express serious doubts about the utility of written advance directives. Recent articles include “Advance Directive/Care Planning: Clear, Simple, and Wrong”, in 2020; “What's Wrong with Advance Care Planning?”, in 2021; and “Should we still believe in advance care planning?”, in 2022.

Morrison et al, the authors of one of those articles, state:

> Treatment choices near the end of life are not simple, consistent, logical, linear or predictable but are complex, uncertain, emotionally laden, and fluid. Patients' preferences are rarely static and are influenced by age, physical and cognitive function, culture, family preferences, clinician advice, financial resources, and perceived caregiver burden.”

For these reasons, there's been a shift in practice from promoting written documents to a dynamic process of dialogue. This is the standard of care for end-of-life decision-making.

It is absurd and alarming that written directives, having failed for ordinary treatment decisions, are now being contemplated for MAID.

To cause the death of a person with dementia who is not asking for it on the basis of advance consent that is necessarily uninformed is contrary to autonomy and beneficence and has nothing in common with treatment withdrawal decisions. There is a broad consensus in ethics and medicine that to directly cause death is distinct from allowing death to occur through the natural progression of an illness.

Advance directives for MAID would lead to elder abuse through manipulation and forgery of directives. I've seen it with powers of attorney, where the consequences are not nearly as grave.

If MAID by advance request became legal and binding, Canada would be the only place in the world where a state agency is obliged by law to kill an innocent and defenceless person.

● (1950)

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

Our final panellist is Dr. Susan MacDonald.

You have five minutes.

[*Translation*]

Dr. Susan MacDonald (Associate Professor of Medicine and Family Medicine, Memorial University, As an Individual): Good evening. Greetings from Newfoundland and Labrador.

[*English*]

I have practised palliative care for 30 years and have had the privilege of caring for thousands of patients and families. I provide secondary assessments for MAID and have had a close relative utilize MAID. My words today will reflect my personal thoughts on the subject rather than support any organization.

I feel that MAID is an end-of-life option that can be part of palliative care but is not exclusive to it. Many of us who practise palliative care are involved, to some degree, in the provision of MAID, whether it is to fully inform our patients of all their options, including MAID, to discuss this option in depth with our patients, to be the second assessor, or to be the primary provider. There will always be a divide among clinicians on this subject, but, regardless of a clinician's personal feelings, the patient has a right to know about this procedure, what the criteria are and how to obtain it.

From a practical point of view, here are my thoughts about MAID and advance directives.

My first concern is about palliative care. Not everyone has access to palliative care. Provincial and local issues dictate whether anyone with skills in this field of medicine is available. Virtual care has limitations and cannot fully compensate for this lack. Some patients could benefit from our services but are limited in access because their physician refuses to refer, because their local program has limitations regarding who can have services and for how long, or because there may not be anyone available to provide in-home care. There may be no paramedics trained to provide palliative care at home. In my jurisdiction, having this service very significantly reduces the number of admissions to institutions. Good symptom management and support at end of life, whether it be in the last years, months, days or hours, is a human right. We're failing the Canadian people when postal codes determine access.

My other concern is that MAID is not routinely offered as an option. Ideally, all choices for patients should be outlined early in order to give patients ample time to consider which options work for them and which do not. Not informing a patient that MAID is an option is unfair to the patient and doesn't follow the guidelines for informed consent. For example, would we consider that a patient newly diagnosed with cancer be offered surgery, radiation and symptom management only, if chemotherapy were also possible? Would we say to ourselves, “We don’t offer chemotherapy unless the patient specifically asks about it”? Of course not, yet this happens over and over with MAID, because there is a perspective among some clinicians that they cannot raise the topic and that to mention it encourages or solicits a patient. Patients require time to consider their options: “What's in keeping with my personal philosophy? What can I afford? What can I obtain? What do my culture, religion and personal values tell me is right?”

We know that some populations in this country have less access to MAID than others. We must continue to be mindful about this and work hard to ensure that all Canadians have the opportunity to avail themselves of all of the end-of-life choices that suit them. Patients should be able to obtain MAID wherever they live.

However, there are still institutions and organizations that deny MAID on their premises. My own relative couldn't go to her local hospice, because she wasn't allowed to have MAID there.

MAID providers should have adequate training and support. This should be standardized across the country. Many providers find they need adequate breaks or supports when involved in this type of care. We need to ensure there are enough clinicians who thoroughly understand what they're doing and how to do it. There has to continue to be clear oversight, data collection and frequent evaluation.

People should be able to determine whether they want MAID at a future date, should they become incapacitated. Many of my patients have told me over the years that the one thing they fear the most, beyond pain, shortness of breath or anything else, is the loss of the ability to make their own decisions. This creates tremendous human suffering.

MAID has been a positive addition to the list of possible ways for me to care for my patients. It's a gift to those who want the option of control: There's always an escape route if things get too bad. Sadly, many patients are very unaware that this option exists. They can't create a tool to ensure they get MAID when they want it.

The MAID deaths I've witnessed have been the easiest and most peaceful of my career. While most of my patients do not end up utilizing this option, more increasingly do.

● (1955)

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

Dr. Susan MacDonald: As a palliative care physician, it is my privilege to help all my patients get the death they want.

Thank you very much.

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

Now we'll go into questions from our members.

The first questioner, for five minutes, will be Mr. Cooper.

Mr. Michael Cooper: I believe it's Mr. Barrett.

The Joint Chair (Hon. Yonah Martin): I'm sorry; it's Mr. Barrett.

Mr. Michael Barrett (Leeds—Grenville—Thousand Islands and Rideau Lakes, CPC): Thanks very much, Madam Co-Chair.

Thank you to the witnesses for appearing today.

Dr. Ferrier, I was wondering if you could tell me about how we can make advance requests safe by ensuring the person signing the request is fully conscious of what they're signing and of the authority that it gives.

Dr. Catherine Ferrier: Thank you for that question. I'm happy to address it through the chair.

I've heard a lot in the last hour about how to prepare people to sign advance requests, but in my view, and in the view of the medical literature on advance care planning, it is still not adequate consent, because you're lacking many elements of what you would need to know to consent to any kind of procedure.

In my experience, people sign all kinds of things without knowing exactly what they're signing. I've seen many of what we call in Quebec "protection mandates", which are supposed to be just to name an alternative decision-maker. For some reason, they have started having end-of-life wishes inserted in them, which are so vague and general that they basically authorize any random doctor who meets you in the emergency room to decide that a treatment is superfluous given your condition.

It's very dangerous. When I ask the patients what they mean by it, they say it means that they don't want to be a vegetable. Essentially, it was not their wishes. It was a text that was given to them by somebody they trusted, and they signed it.

I would expect the same thing to happen regardless of all the safeguards that I've heard about in the last hour or so, because right now with the MAID regime in Canada, there are all kinds of people dying by MAID, horrifying the whole country. I can tell you even more stories from my own experience and from the experience of the people around me about how safeguards don't work and documents can be abused.

In my practice in geriatrics, I've seen documents abused all the time. I could tell you many stories, but I don't think I have more time to tell them right now.

● (2000)

Mr. Michael Barrett: Okay. Thanks, Doctor.

In your opening comments, you talked about advance requests for MAID being used in elder abuse cases. Can you elaborate on that for me, please?

Dr. Catherine Ferrier: Yes, I'd be happy to elaborate.

Obviously, that has not happened because advance requests are not legal in our country, but there are documents that delegate decision-making authority to another person, and I've frequently been to court with families squabbling over who has authority over the patient. It's often about money. It's often about how much of the inheritance will be used up in paying for the care of this older person. It's not 100%, but I think the same thing will happen with requests for MAID. It is expensive to care for people. Family members and people around my patients are not always benevolent and are not always acting in the interest of the patient. I've seen forged mandates. I've seen mandates signed without an understanding of what people were doing.

There are a lot of dysfunctional social groups in this world, including families. I can see that this would just explode with the number of people getting dementia now. It worries me a lot. My patients are very vulnerable, and you can talk as much as you want about autonomy, but even without dementia, they are often not as autonomous as theoreticians think they should be.

Mr. Michael Barrett: Right, and I appreciate the clarification in your response that advance requests are not the law of the land here, but they are elsewhere. Advance requests are legal in other countries. Can you relate that to your previous answer?

Dr. Catherine Ferrier: Are you asking specifically about elder abuse?

Mr. Michael Barrett: Yes. Building on your previous answer, what has been the effect of advance requests in other countries?

The Joint Chair (Hon. Yonah Martin): You have 40 seconds.

Dr. Catherine Ferrier: I think I couldn't say it better than what Professor Lemmens said in the last hour about how in the Netherlands, for example, the popularity of advance requests is going down—not up—because of all of the hazards, problems and examples of the lack of safety that are being demonstrated in that country. I think that's very valid evidence for what we decide in Canada.

Mr. Michael Barrett: Okay. I think I'm out of time. Thank you very much, Dr. Ferrier.

Thank you, Madam Co-Chair.

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

Next we'll have Mr. Anandasangaree for five minutes.

Mr. Gary Anandasangaree (Scarborough—Rouge Park, Lib.): Thank you, Madam Co-Chair. I'd like to thank the panel.

I'm going to focus my questions on Dr. Downie.

You indicated in your testimony that advance requests should be made at or after a diagnosis. Can you indicate if there are any situations in which such a request can be made before a diagnosis?

Dr. Jocelyn Downie: From a public policy perspective, I'm not advocating for that right now. I wouldn't be arguing against it and I wouldn't want to try to defend not having a broader approach in court. You heard the arguments around that. However, I think that they are different, and one of the principal areas where they're different is, for instance, the amount of information that you may have available to you in order to make a decision.

Once you have the diagnosis of a serious and incurable condition, I think you absolutely can make a free and informed decision about an advance request for MAID. We'd need to think differently about it if it comes earlier.

● (2005)

Mr. Gary Anandasangaree: Can you elaborate on the mechanics of what an advanced request would look like at the end of life, at a point when somebody loses their capacity to make a decision?

Dr. Jocelyn Downie: Do you mean when it's being triggered and used? What's really important is we need to think of these differently in terms of the procedural safeguards and what the documents would look like and what the processes would be.

There are indeed failings in the advance directive regimes. I'm not looking to graft this on to those. I think what you would do is have the person write a document in collaboration with a clinician. It's a written arrangement—an agreement between people—and it would set out what the person considers to be intolerable suffering and objective criteria to determine whether those criteria are met.

For example, my intolerable suffering might be about a loss of personal identity, personal integrity and my own conception of dignity. What I couldn't do is just say, “When I no longer have personal integrity.” How can somebody else assess that? What they can assess, for instance, is if I say I can no longer name my spouse or children any day at all for two weeks straight. I could say that, or I could say that when I am at stage 7 dementia. That is an objectively assessable condition that I tie to my personal determination of what constitutes intolerable suffering.

What would happen is that somebody would say, “This person has lost decision-making capacity. There is an advance request. Here are the objectively assessable conditions for the provision. Have they been met?” The clinician would be able to assess that.

Mr. Gary Anandasangaree: Dr. Downie, at that point, is it a clinical decision, a decision of a substitute decision-maker, or a combination of both?

Dr. Jocelyn Downie: It is, I think, never a decision of a substitute decision-maker. There is no room for substitute decision-making in this context. It is the individual who was saying what is to be done to them at a point at which they have lost decision-making capacity, and the clinician assesses the objectively assessable conditions because you've sorted that out by writing down your written request. You figured out what will work. It is something that clinicians can assess, and they determine whether those conditions have been met or not.

There is no substitute decision-making here at all.

Mr. Gary Anandasangaree: Thank you, Dr. Downie. I'll pass my time to MP Maloney.

The Joint Chair (Hon. Yonah Martin): There are one and a half minutes.

Mr. James Maloney (Etobicoke—Lakeshore, Lib.): Thank you. My question is for Dr. Ferrier.

Doctor, you said advance consent can never be fully informed. Informed consent is a legal concept designed to protect a patient, as I understand it. Arguably, nobody can ever be fully informed when they give consent in medical situations, but they do their best, and this is no different.

My question to you, Doctor, is about a situation in which I have a terminal illness that I know cannot be cured. My fear is not dying; my fear is living in misery. If one of the factors that I consider in making my decision to provide consent in advance is that I will not be able to communicate when the time comes, is that not properly informed consent? I'm taking that into consideration. I'm fully aware of the circumstances and what they might be then.

Dr. Catherine Ferrier: You're informed, theoretically, about what the experience of dementia might be to you.

Mr. James Maloney: No, Doctor. I have terminal cancer and I know I'm going to die. I know I might be in a situation in which I might not have the cognitive capacity to change my mind, but I've made the decision that I won't have the ability to change my mind and I know I don't want to live in misery. Is that not informed consent?

Dr. Catherine Ferrier: That is already legal, for one thing. It's not what we're talking about here, I don't think, but—

Mr. James Maloney: No, no; you're talking about an advance directive versus an advance instruction for MAID.

Dr. Catherine Ferrier: But the waiver of consent is already in the law. You cannot—

Mr. James Maloney: No. I'm talking about the provision of MAID, not the withdrawal of medical services.

Dr. Catherine Ferrier: Yes. I understand. That's what I'm talking about too.

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

Next we'll have Monsieur Thériault for five minutes.

[*Translation*]

Mr. Luc Thériault: Thank you, Madam Chair.

I'll begin with a question for Professor Downie.

Let's take someone experiencing cognitive degeneration who makes an advance request for medical assistance in dying. Clearly, a time will come when that person begins to lose what we call the attributes of personal life, such as self-awareness and relational capacity, not to mention existential suffering. When they have reached the terminal stage of the illness, let's say Alzheimer's disease, they would be only biologically alive, in a mostly vegetative state.

When an advance request has been made, should one wait until patients have reached this ultimate state to consider medical aid in dying morally acceptable, or can it be administered at an earlier stage in the disease, based on criteria specified by the patients themselves?

● (2010)

[*English*]

Dr. Jocelyn Downie: I believe absolutely that it is for the individual to determine what constitutes a life of enduring and intolerable and irremediable suffering for them. It's very clear that it can be physical suffering or psychological suffering or existential suffering. It's for the person to decide what that will be and to then very carefully lay that out, so that when they are no longer competent and capable of decision-making for themselves, that written request will be able to speak for them.

It need not be at the end stage. They may consider a life of intolerable suffering to come much soon than end-stage dementia, for instance. They're allowed to make that decision.

[*Translation*]

Mr. Luc Thériault: Yes, that's possible. A person with dementia can live a long time after having reached the terminal phase of the illness and, at the end of the line, not die from that illness but from collateral effects. That's what leads me to my next question.

Are you advocating two different regimes to cover two types of medical conditions, a regime of advance requests for medical assistance in dying and a regime for advance medical directives like the one we have in Quebec?

I'll add my next question right now. Do you believe it's necessary for a patient to have previously received a diagnosis?

[*English*]

Dr. Jocelyn Downie: The first thing I would say is do not—please, do not—blend the two regimes and think that if it's dementia, you go through advance request, and if it's something else prior to diagnosis, you go through the mandate or the advance directives in any other province. Do not blur them. This is a federal issue. It is dealt with under the Criminal Code. MAID can only be dealt with that way, I believe.

You could have two regimes for advance requests under the federal Criminal Code. One would be for when you have had a diagnosis with a serious and incurable condition. The other could be prior to diagnosis. I think they would have different procedural safeguards. You have different amounts of information available to you. They might be at different times. They're much more likely to be at different times if it's pre-diagnosis and that kind of thing, so I could see two federal regimes, but I don't see MAID ever being dealt with under a provincial advance directives regime.

[*Translation*]

Mr. Luc Thériault: Are you advocating expanding access to medical assistance in dying to enable people to make a request prior to having a diagnosis, or do you feel it's absolutely essential to first have a diagnosis?

[*English*]

Dr. Jocelyn Downie: I think the case is made most strongly when you have a diagnosis for a serious and incurable condition. You can respond to a lot of the concerns people have about advance requests: You don't know what condition you're even going to have, so how can you possibly project yourself out into the future and know that it constitutes intolerable suffering? You do have that piece of it—that you can predict better—and that helps people feel more comfortable, and it actually undermines some of the arguments against advance requests.

I would add one thing in relation to something you've been saying—

The Joint Chair (Hon. Yonah Martin): Be very quick, Dr. Downie.

Dr. Jocelyn Downie: For people who are before diagnosis—and we have been talking about strokes and so on—we also need to inform people about alternatives to MAID in those circumstances. Those include palliative sedation and voluntary stopping of eating and drinking. Quebec has done a much better job about palliative sedation than the rest of Canada. We should be talking about the entire spectrum of end-of-life care.

● (2015)

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

Next we have Mr. MacGregor for five minutes.

Mr. Alistair MacGregor: Thank you very much, Madam Co-Chair.

Dr. Downie, I'll continue with you.

This is very much an issue of personal agency and people making very personal and tough choices.

I guess for me, when you speak to a lot of people, you have to acknowledge that out there is a lot of stigma surrounding dementia. People are very afraid of getting that diagnosis. They have very real concerns with long-term care. We've seen the worst of the worst through the last two years of just how bad it can get. There is a very real fear out there about the level of care that exists.

One thing I'm personally struggling with is that if we do permit a regime in which advance requests are made or permitted, what do you think about people's fear of the lack of caregiving options that exist out there for people with dementia? How do you think that's going to influence their decision in making that advance request? How do we appropriately deal with that very real issue as a committee?

Dr. Jocelyn Downie: Yes, it's very real.

There are several ways, and the first is to point out that the stigmatization in some sense goes in both directions. If you don't let people have advance requests, you're in a sense saying that people with dementia can't be trusted to make decisions for themselves in the future because they're too vulnerable to these external pressures and so on. I think that itself is stigmatizing of persons with dementia.

The second point is that it is the person's decision. It's not society saying, “Your life as a person with dementia is not worth living.” It is only for the person. I would never say to somebody else who has dementia that their life is not worth living; it is for the person to say whether it's intolerable suffering. That way, it doesn't carry a stigmatization, because it's internal.

With regard to supports and services, this is your opportunity to be bold. It is to be bold about the parallel tracks. You're a committee sitting in the House and the Senate. You have federal levers to improve the supports and services for people with disabilities and mental illnesses. My whole argument all along has been parallel tracks.

An individual has access to MAID while they're capable, or through an advance request. At the very same time, we put a huge push on. We shine a very bright light and demand accountability for improving the supports and services that are so desperately needed. They're not mutually incompatible. In fact, by having a conversation about MAID, we now have an opportunity for people to listen to a conversation about supporting persons with disabilities and mental illnesses in Canada. That's where I hope this committee is bold and figures out ways to use the federal purse and convening powers. You have all kinds of tools. Use those to fix the problems that are coming to light and that people are finally paying attention to. Don't constrain access to MAID, because you should never make individuals hostage to fixing systemic problems.

Mr. Alistair MacGregor: To expand on that, it's not just people's fear about getting a dementia diagnosis but also that many marginalized communities in Canada—the disability community and other groups—have experienced a systemic lack of equitable access to health care through their entire lives.

Is there anything further you want to add on the very real fears those groups are presenting to us as well?

Dr. Jocelyn Downie: I think they need to hear the evidence about the impact on vulnerable populations. It is not what is being presented. I would plead for you to talk to the primary authors on the empirical research that's been done in the Netherlands, Belgium and in Canada, none of which demonstrates that there is this vulnerability. If anything, there's a vulnerability to not getting access to MAID among those populations. That would be the first thing.

The second thing I'd say is that denying access to MAID is not going to mean that people get access to these supports and services. All they're left with is the life that they have just described to you as one of intolerable suffering. They're left in that life because at the individual level, they're not suddenly going to be offered all of these other options.

I say back to that, “We hear you about your concerns.” Circling back to what I said before, “You are right to be dissatisfied with how Canada and the provinces have supported you, but don't be concerned that this is going to put you at risk.” Allowing access to MAID through advance requests or the sunset clause won't cause that.

● (2020)

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

I'll now turn this over to the co-chair for questions from senators.

The Joint Chair (Hon. Marc Garneau): Thank you, Senator Martin.

We'll go to the senators. These are three-minute rounds, and we'll begin with Senator Kutcher.

Please go ahead, Senator Kutcher.

Hon. Stan Kutcher: Thank you very much, Mr. Chair.

Before I start my three minutes, I would ask that Dr. Ferrier provide us with evidence to support the statement about elder abuse through the forgery of advance directives. We'd like to see the research for that, please.

These questions are for Professor Downie.

We've heard opinions that a clinician or third party should define what an irremediable medical condition is for a patient. Others have opined that it's the patient who determines what an irremediable medical condition is for them. I'd like your thoughts on that.

My second question is this: We've heard the opinion that procedures or safeguards cannot provide society with comfort with respect to advance requests being properly discharged. What is your thinking on that issue?

Dr. Jocelyn Downie: On irremediability, two things are going on.

One is for the patient and one is for the clinician. The patient decides what treatments, if any, they're willing to try. Then the clinician says, “Here's what I understand about whether that will or will not work.” That's a clinical choice, but whether the person wants to take the treatment is a moral, personal choice for the individual.

We have to think about incurability similarly. We have to think about them as having different roles, and ground them in the expertise each one has. The patient has expertise in what constitutes suffering to them, what their values are and what gives them meaning. The clinician has expertise in what a treatment can do for this condition—the trajectory, and so on.

On safeguards, I would say we don't have evidence that there is any risk of what you mentioned, in part because I have not seen the evidence some of what we've heard as described as harms and abuses. I don't believe it's there. It's how people are reading things. I think that with safeguards, we absolutely can.

The other thing I'd say is that we're already doing it. If we think we don't have adequate safeguards, then we need to be changing a whole bunch of other things we're doing, including advance directives, substitute decision-making in ICUs, and final consent waivers. All of those are premised on having safeguards that are adequate. Those same but enhanced safeguards will do the job.

The Joint Chair (Hon. Marc Garneau): Have you finished, Senator Kutcher?

Hon. Stan Kutcher: Yes, I have. Thank you very much.

The Joint Chair (Hon. Marc Garneau): Thank you very much.

[*Translation*]

Ms. Mégie, you have the floor for three minutes.

Hon. Marie-Françoise Mégie: Thank you, Mr. Chair.

I'd like to thank the witnesses for being here with us.

My question is for^x Dr. Downie.

How do advance requests for medical assistance in dying and advance medical directives resemble or differ from one another under the current provincial and territorial regimes?

If requests for medical assistance in dying were authorized following a diagnosis of dementia or without a diagnosis, how would the respective regulatory frameworks differ?

[*English*]

Dr. Jocelyn Downie: Advance directives happen at a provincial or territorial level. They are largely about withholding and withdrawing treatments: People get to make a decision now about what treatment decisions they want made and how they want them made in the future, should they lose decision-making capacity.

It's important to note there are two kinds, instruction and proxy. Instruction is when I say, “These are the decisions I want.” They are written down. I tell you. Proxy is when I say, “I want my sister to make decisions on my behalf.” Nobody advocating advance requests for MAID is suggesting we would have proxy directives. We would only have an instruction. That's the provincial context.

The advance request context is federal. It's dealt with through the Criminal Code. It is only for MAID. It is only a written request developed and signed in the context of a clinician-patient relationship—probably multiple clinicians—over time, as the person is fully informed and as all the eligibility criteria for MAID are checked, such as voluntariness, having the information, and so on.

They cover different health care interventions and they have different rules. They are regulated in different ways, because the federal one would be regulated by the federal government and the provincial ones are done provincially, through colleges and so on.

● (2025)

[*Translation*]

Hon. Marie-Françoise Mégie: Thank you.

Do I have enough time to ask Dr. McDonald a brief question?

The Joint Chair (Hon. Marc Garneau): You have 45 seconds left.

Hon. Marie-Françoise Mégie: Okay.

Dr. McDonald, could you briefly tell me where the palliative approach fits into the end-of-life context for a person with dementia?

I know that you work with people who have dementia.

[*English*]

Dr. Susan MacDonald: I do.

Part of the end-of-life process is ensuring that patients are aware of what their options are and what they can choose from. It means understanding what their disease is, what they can expect from the disease, how that disease is going to progress, what kind of symptoms they're likely to experience and then, from the clinician's point of view, what can be offered to help with each of those symptoms.

That's why I said earlier that I think patients often don't know about medical aid in dying as an option. We know a lot about it because we're very invested in it and we're all here to talk about it, but the average patient—you'd be surprised—doesn't know that's even an option, and a lot of clinicians do not raise it. They wait until the patient has said the secret words about “this euthanasia thing”, and then they'll talk about it.

It's not informed consent when they don't have all the information they need to pick and choose what is right for them. People need time to think about all these options.

The Joint Chair (Hon. Marc Garneau): Thank you, Dr. MacDonald.

Senator Wallin, you have three minutes.

Hon. Pamela Wallin: Thank you very much.

I have a question for Dr. Downie, but first I'm going to ask her to clarify something I read in the record of our meetings. I think it was a question to a witness. Here it is.

> the Supreme Court of Canada stated unequivocally three times in Carter that medical assistance in dying may be performed only when a patient clearly consents. [...] In the face of the pronouncement of the Supreme Court, do you believe that an advance directive can be a true expression of free and informed consent consistent with Carter?

That was the quote.

Could you clarify whether that was your interpretation of Carter in relation to advanced consent? Then I have a question about.... Well, just answer that, if you would, please.

Dr. Jocelyn Downie: That's simply not true. That is not what the Supreme Court of Canada said.

The Supreme Court of Canada said that a prohibition is void if it prohibits somebody from accessing MAID who clearly consents. That is not the same thing as saying that MAID is permitted only when someone clearly consents. They answered the question they were asked, which was about people clearly consenting. They said that if you prevent people here who can clearly consent, you're breaching the charter. That says nothing about what the requirements need to be.

I heard that earlier today, actually, and I heard it from another witness. It's bizarre to me.

Hon. Pamela Wallin: Thank you for that clarification. I think it's extremely important. I know you have concerns about pre-diagnosis advance requests.

I have two quick points. One, once you're diagnosed, I guess people could challenge your competence. More importantly, wouldn't a history detailing an advance request and concerns about a prolonged life under intolerable suffering, by that person's definition, be helpful in assessing whether the post-diagnosis request was valid?

● (2030)

Dr. Jocelyn Downie: Absolutely. I think the longer that you have conversations about what a person wants, the better situated you're going to be for understanding the request and, more importantly, the better the request is going to be.

What we don't want is the kind of situation that Dr. Ferrier mentioned, of somebody saying they don't want to be a vegetable. We can't work with that. It needs to be very clear. We need to understand the values and the meanings that are behind the requests.

Hon. Pamela Wallin: That was Dr. MacDonald's point about education.

Dr. Jocelyn Downie: Absolutely. Yes. Over time, that is true.

Partly why I'm all in on it after a serious diagnosis and I might seem to be more lukewarm on pre-diagnosis is that I'm juggling. From a public policy perspective. I think it's absolutely defensible, but in fact we need to do it after diagnosis because of the reports that have been done, the public sentiment, the clinicians—all those.

From a personal philosophical perspective, I would see advance requests before; I think we can sort out those problems. However, I'm trying to navigate bringing to you what I think the best public policy arguments are at the moment, and there is a real reliance on the work of those prior committees and expert panels.

Hon. Pamela Wallin: Thank you.

Thank you for the clarification as well.

[*Translation*]

The Joint Chair (Hon. Marc Garneau): Thank you very much.

Go ahead, Senator Dalphond.

Hon. Pierre Dalphond: Thank you, Mr. Chair.

[*English*]

My question will be for Dr. Downie.

We all agree that if we have advance requests, they should be in the case of an irremediable condition, and that should be well defined. What seems to be bugging some people is the concept of “intolerable suffering”. You say that when you lose capacity, sometimes you're not suffering in your new situation. Maybe we should say that it's an irremediable condition, which is, according to the person doing the advance request, an unacceptable irremediable condition. Wouldn't that be better than to refer to “intolerable suffering”?

Dr. Jocelyn Downie: I think you could certainly conceptually make that argument. I think people may express concern that the sands are shifting. That's why I've tended to stick with the language of saying that it's for the person to decide what constitutes “intolerable suffering”, so then I might say from a public policy perspective that I would advance “intolerable suffering”.

From a philosophical perspective, I would absolutely agree with you: What are the conditions under which you are having control over what happens to you in the future when you are no longer capable and you think you want that life to end because the conditions are unacceptable?

Hon. Pierre Dalphond: Behind it will be the principles of autonomy and the right to dignity—

Dr. Jocelyn Downie: Yes.

Hon. Pierre Dalphond: —instead of removing “intolerable suffering”. Some people are completely at stage 7, but they are not suffering. They are no longer the person they were, but they are not necessarily suffering, according to those who observe them.

Dr. Jocelyn Downie: Yes. I think with the end stage you can still say they're suffering according to their conception of suffering, because it would be an existential suffering.

I think the situation that makes your case would probably be unconsciousness. When you're truly unconscious, it's probably harder to make the case that you are suffering, but you would say, “Those are conditions under which I consider continued existence to be unacceptable, and so I am requesting MAID.”

Hon. Pierre Dalphond: Thank you.

[*Translation*]

The Joint Chair (Hon. Marc Garneau): Thank you.

I'm now going to give the floor to Senator Martin.

[*English*]

Senator Martin, you have three minutes.

The Joint Chair (Hon. Yonah Martin): Thank you. My question is for Dr. Ferrier.

My colleague was talking about intolerable suffering. My mother suffered from dementia and was in fear when she was having to get surgery for her fractured hip. I just wanted her to not suffer and to end her misery. It was from my own position of making a judgment, and yet she bounced back so quickly, and at every stage I saw her real joie de vivre.

Could you speak from your experience regarding people living with dementia and suffering?

Dr. Catherine Ferrier: Yes. Thank you for that question.

I think people with dementia suffer if they're treated badly. It's like everyone. If you're badly treated, you suffer, and if you are cared for, surrounded by affection and surrounded by everything you need, then generally you don't. There are symptoms of dementia, such as agitation and so on, that we can generally manage. In some extreme cases, we cannot.

A lot of things have been said during this panel about not wanting to be that person with dementia. I think there's a lot of stigma there. People are saying, “My suffering now is to think of myself as being in the position of those people in the nursing homes, and I don't want to be that person.” That makes me very uncomfortable.

I don't see my patients suffer; I've seen lots and lots of patients with dementia, and it's very rare. Sure, you go through a bad time, and sure, hips we fix because it gets people walking again. We don't always send people to the emergency room from a nursing home. If they have a fever, we might treat them in the nursing home even if they die sooner of whatever infection they have, because the stress of going to the emergency room would be terrible for that person. It would make them more confused. They would maybe spend hours on a stretcher.

There are many things that would cause suffering to a person with dementia, but we don't have to do all those things. We do the things that we really think are in their best interests and that lead to their comfort. We're not going to do a triple bypass. We're not going to do many things that a person who has normal cognition could go through much more easily because they understand what's happening.

I think the concept of suffering is very subjective. It troubles me to hear people talk about my patients in many of the terms that have been used tonight about how “I don't want to be like that”.

● (2035)

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

The Joint Chair (Hon. Marc Garneau): You had 30 seconds, but thank you, Senator Martin.

Thank you to all the panellists this evening for your expertise, for your testimony and for answering our questions. We very much appreciate it, Professor Downie, Dr. Ferrier and Dr. MacDonald. It's a late hour for some of you on the east coast, so we very much appreciate that you took the time to be with us this evening. Your contributions are very important to our deliberations.

Thank you.

With that, we'll suspend momentarily and get ready for the next panel. Thank you.

● (2035)

_____________________(Pause)_____________________

● (2040)

The Joint Chair (Hon. Marc Garneau): I call the meeting back to order.

Welcome to the panellists. I'll take a minute to say a few things.

First, before speaking, please wait until one of the joint chairs recognizes you by name.

Second, I remind you that all comments should be addressed through the joint chairs. When speaking, please speak slowly and clearly. This is for the interpreters. Interpretation in this video conference will work like an in-person committee meeting. You have the choice at the bottom of your screen of “floor”, “English” or “French”. When you are not speaking, please keep your microphone on mute.

With that, I would like to welcome our witnesses for panel three this evening.

We have, as an individual, Dr. Romayne Gallagher, clinical professor of palliative medicine at the University of British Columbia; we have Dr. Lilian Thorpe, professor at the University of Saskatchewan; and we have.... Perhaps I should say this in French.

[*Translation*]

We are also welcoming Dr. Laurent Boisvert, who is a physician.

[*English*]

Thank you for joining us.

We will begin with the opening remarks of the three panellists. You will each have five minutes. Try to stay within those five minutes. We will start with Dr. Gallagher, followed by Dr. Thorpe and then Dr. Boisvert.

Dr. Gallagher, the floor is yours for five minutes.

Dr. Romayne Gallagher (Clinical Professor, Palliative Medicine, University of British Columbia, As an Individual): Thank you to the joint committee for allowing me to speak.

I'm a retired physician with over 25 years of experience in providing palliative care in all locations of care. I've been an attending physician and palliative care consultant to people with dementia, as well as physician director of long-term care and a physician leader in academic palliative care.

I cared for my elderly neighbour who wanted to stay in in her house where she lived alone, despite her dementia. She had no children or spouse, so we were her family. I was her power of attorney for the last four years of her life. She died at 96, having lived in the same house since she was eight years old.

With respect to advance requests for MAID, despite the compelling evidence of wanting to be able to make some choice, medical and social science literature reminds us that people are poor at anticipating what life would be like with a life-changing illness or disability. People adapt to illness and disability and adjust their needs for a decent quality of life. Many medical conditions have long and unpredictable courses. Suicidality caused by these conditions can last for protracted periods of time.

In jurisdictions where advanced requests are permitted, physicians have difficulty following advanced directives for hastened death because they cannot reaffirm consent and they cannot establish current suffering. Family members have the same conflicts and find it a burden.

I want to focus on the suffering of people with dementia.

People with dementia can self-rate their quality of life. We know that they consistently rate it higher than caregivers do. Cognitive abilities have little impact on their quality of life, but good relationships, social engagement and spiritual and religious beliefs help maintain quality of life. We do know, though, that losing functional ability, pain and depression can reduce quality of life.

A 2018 study of the lived experience of over 600 individuals with dementia revealed the importance of their physical environment and the people they interact with. A positive environment allows people with dementia to continue to participate in life, and it includes caregivers who facilitate retaining control and a sense of purpose. Through adapted physical environments like dementia villages, people with dementia can continue to walk outside and express their emotional, relational, spiritual and creative selves.

Technology can also aid in reminding them of their identity and memories. The fear of losing capacity and losing control over their lives may not be realized because they are still recognized and treated as a person.

Dr. Tom Kitwood was a researcher in maintaining personhood in dementia. He concluded that personhood is “a standing or status bestowed upon one human being by others.... It implies recognition, respect and trust.“ He described how our actions undermine the personhood of a person with dementia. These are actions such as conversing with others as if the person with dementia were not present, infantilizing, disempowering by not letting someone walk unsupervised, treating people like objects, and taking away control of every decision. It is our society's behaviour that contributes to the suffering of people with dementia and fuels the stigma supporting the idea that with dementia, a person dies inside a living body.

Those with money can buy adapted environments with supportive care. If we allow advance requests, those who can't afford adapted environments will have only an illusion of choice. They will choose between depersonalizing care or MAID.

Providing a palliative approach to care that focuses on maintaining quality of life and providing care that meets preferences of people is essential, yet a CIHI study in 2017 showed that only one in 20 people with dementia actually receives palliative care.

I wrote a brief to this committee that argues that those suffering without access to quality palliative care or who receive it only after they've requested MAID is a medical error. The error is not in receiving MAID, as the person may meet all the requirements. The error of omission occurs in the months before, when the pain, shortness of breath, anxiety and feeling of a burden to others began but was not recognized and addressed. This is an error, because we know that palliative care can help with this and improve quality of life.

● (2045)

Every chronic disease organization recommends timely access to palliative care. I want one of you to ask me how the federal government could achieve greater access to palliative care.

The Joint Chair (Hon. Marc Garneau): Thank you, Doctor. We need you to wrap up.

Dr. Romayne Gallagher: Okay.

Parliament has voted three times in favour of funding a palliative care strategy. It's 2022, and it's yet to be implemented. Canadians will suffer with life-limiting illnesses whether they access MAID or die naturally. They are counting on all of you to ensure quality and timely palliative care, and to ensure that it's provided to all Canadians.

Thank you.

The Joint Chair (Hon. Marc Garneau): Thank you, Dr. Gallagher. We'll now go to Dr. Thorpe.

Dr. Thorpe, you have five minutes.

Dr. Lilian Thorpe (Professor, University of Saskatchewan, As an Individual): Thank you very much.

Thanks for the wonderful presentations I've heard so far.

I'd like to say I'm a geriatric psychiatrist. I see and work with people with dementia. I very much agree with many of these comments about personhood and developing environments where people can live productive and quality lives, even in dementia.

I think it is very clear that most people I know do want to have access to advance requests for MAID. I also think this is going to be really challenging. We're going to have to really think about those guidelines and how we're going to do this.

First of all, people really do change. I see people in hospital with my consultation service who years ago made an advance directive that is often not what they want anymore. They say, “That was then. This is now.”

People change. People don't necessarily understand what they adapt to over time, which is what Dr. Gallagher spoke to. Many really do change, and they adapt to stages in their lives, such as dementia, that they wouldn't have expected before.

These people are not necessarily the same people who asked for this. I think what we do in real life is look at balancing the current person with all of their needs. Somebody with a dementing process needs a lot of help with what they previously wanted. It's a balance. That balance is often discussed within a mixed group of people who then really think about all the issues that have to be thought about in making a very complex decision.

Practically speaking, I think in some cases it's going to be fairly straightforward to approve an advance request if a person still has some ability to say what they want. I mentioned that I've seen close to 700 MAID assessments. I am a MAID assessor and provider. Many of my patients with dementia in early stages do still have some ability to say what they want. Some of them do talk about wanting to have access to MAID. When they're in that early stage, even if they don't have fully informed consent, they may have assent. Those ones, I think, will be the ones we can deal with.

There are people who are in a chronic vegetative state at the end. They may not be suffering anymore, yet we will also find those reasonably doable for us as providers. We will find that we feel we can live with this.

The problem comes in people who have this gradual loss of capacity and insight into the dementia. My patients often say, “Actually, I don't feel so bad anymore. I'm not even sure I have dementia anymore”, as they progress. They may enjoy their environment. They no longer focus on developing dementia, because they don't really know they have it anymore. Those will be very difficult for us to deal with, as would those who develop a lot of agitation and resistance. It's hard to even get them to take their medications, let alone large amounts of oral medications for MAID, or get an IV started for MAID. Those will be highly difficult, and this would be highly traumatic to both family members and care providers.

I have a number of suggestions, and I put them in my written report. I think that in straightforward situations, such as when a person is making a suggestion consistently that they do wish to die, as will happen sometimes, or when a person is in a chronically vegetative state and their advance request is sufficiently detailed to support the situation, these requests could be approved by the usual trained and objective MAID assessors.

There are, however, going to be far more complex situations in which there is no consistent communication from a person saying they wish to die, or there is a lot of conflict among family members about whether the advance request was really going to be consistent in the current situation. In these cases, I think there needs to be a very different process with consultations with some of us, such as geriatric psychiatrists—as is my practice—a geriatrician, psychologists and so on. I would like to see evidence of ongoing, significant suffering, and no evidence that the person is actually consistently enjoying life. If a person is consistently enjoying life and enjoying activities, I would feel very uncomfortable with that as a MAID provider. I would like to see no resistance of any kind to the MAID assessment or provision, with people trying not to have the IV started or to take oral medications. I don't think any of us would feel comfortable then.

I think what this means is that we need interactive meetings among the care team, family members, health proxies and MAID assessors and that we work through this. Maybe there is an ethics issue there. Maybe there are a number of people, not just one or two, making these complex decisions. Maybe social work is there to help with counselling of family members who are very distressed.

● (2050)

I will just tell you that we do have a waiver of final consent. I've had two daughters sobbing in talking about this waiver, because they say they would feel like they would be killing their father. Those patients who have had conflictual relationships with family members are going to be the most distressed by this. There also needs to be an appropriately constituted end-of-life committee that could look at these complex cases. These are going to be really hard, and we're going to have a lot of discussion about this.

That's what I'm going to say. I'm sorry. It's very practical. I'm not going to be able to tell you all of the details in the other countries. I'm just talking to you about myself as a geriatric psychiatrist and someone who sees patients day in and day out. I wanted to talk about those practical aspects.

Thank you for having me.

● (2055)

The Joint Chair (Hon. Marc Garneau): Thank you, Dr. Thorpe.

[*Translation*]

Dr. Boisvert, you now have the floor for five minutes.

Dr. Laurent Boisvert (Physician, As an Individual): I'd like to begin by thanking the Special Joint Committee on Medical Assistance in Dying for inviting me to testify in connection with its efforts to address the issue of advance requests for medical assistance in dying.

My name is Laurent Boisvert, and I'm a physician who specializes in family medicine. I worked as a general practitioner and emergency specialist for 35 years, and as a professor at the university-affiliated centre on Montreal's South Shore.

When the Act Respecting End-of-Life Care Came into force in Quebec in 2015, I made sure that medical assistance in dying would be available not only in institutions, but also elsewhere. I have been actively practising medical assistance in dying for seven years, which represents some 400 cases of euthanasia.

Before addressing the issue of advance requests, I would like to describe two cases of individuals with dementia for you.

I would like to begin with Mr. Yves Monette's case. I've used his name, because his story has been heavily covered by the media. Mr. Monette had frontotemporal degeneration, leading to varied atypical symptoms. In addition to temporarily losing control of his members, he would sometimes take a shower with his clothes on or go and take a walk outside in his nightshirt. Although he had formerly been very active and happy, a martial arts instructor and a security guard, he was now ill, isolated and unable to do anything. His life had become insignificant to him. He asked for medical assistance in dying many times, but owing to the legislative context at the time, meaning before March 2021, he was no longer eligible. The disease nevertheless made his life increasingly difficult.

I met him in April 2021, after reading a newspaper article about him. When I met him, I confirmed that his request was admissible, but as his death was not reasonably foreseeable, there would be a waiting period of 90 days. He immediately accepted, happy to know that he would no longer have to suffer this form of existence. In the same breath, he asked to donate his organs, because he was otherwise in excellent shape.

We met on several occasions, and he never changed his mind about his decision. Despite his dementia, he was capable of clearly reiterating his request until the very end. That's not the case for many people with this type of illness, as we will see in the second case.

He died serenely, although he was sad to go. He was surrounded by several friends and relatives. He was dressed in a uniform loaned to him by the Longueuil police and was wearing boxing gloves.

I now like to tell you about Ms. C, an 84-year-old patient. She had always been active and happy, a mother who lived with her spouse. I met her in May 2021 in connection with her request for medical assistance in dying.

The previous fall, at a family gathering, Ms. C's children had noticed some bizarre behaviour. She was somewhat uninhibited, even though she had always been very prudish. She also said some things that were incoherent, but it was not too noticeable. She met her family doctor with one of her daughters and her spouse. After some examinations, she was diagnosed with Alzheimer's, a form of dementia, which was no surprise to anyone.

When I met the family, the patient understood her disease and explained why she did not want to stretch out her life uselessly until she would lose her autonomy in terms of everyday activities, and become a burden to her spouse and her family. She fully understood the nature of her request and its irremediable consequences, but wanted to take advantage of life for as long as possible. She therefore did not specify a date for receiving medical assistance in dying.

I told the patient and her family about the act and its limitations. The patient would have to be able to consent to medical assistance in dying until the decision was made to request it. That meant that she would have to be very closely monitored, because once it was becoming obvious that she was no longer capable of expressing her wishes, it would be necessary to proceed with medical assistance in dying. However, and here's the problematic issue, the current legislative framework would force us to steal some quality time from this patient and her family.

I told her family doctor about the situation and we monitored the patient closely, who remained capable of clearly stating her wishes for a while. However, everything changed quickly in only a few weeks. The patient saw her family doctor, together with her family, and she was no longer able to clearly state her wishes. She was confused, disoriented and even incoherent. She was no longer capable. As a consequence, she could no longer receive medical assistance in dying and would have to go through what she specifically did not want to put her family members through. Her illness led to a gradual state of decline. Her family members no longer recognized her and even worse, sometimes had to deal with a person who could be aggressive and unpredictable, or even a curled-up body that could no longer interact with the outside world.

With respect to advance requests, I agree with Dr. Alain Naud, who presented his views to you along with those of the Collège des médecins du Québec, to the effect that the act should enable a patient, who has received a diagnosis of confirmed neurocognitive disorders or dementia, to submit an advance request for medical assistance in dying. This binding request, that no one can challenge, would have to specify application criteria, meaning the clinical status that would trigger the procedure. Only patients are able to specify what they are willing to put up with, what is unacceptable to them and what they would define as an unacceptable decline.

Enforceability would have to be defined and established by the appropriate health care authorities.

● (2100)

Enforcement would have to provide the possibility of an appeal by one or more proxies designated by the patient at the time of drafting the advance request. These would be responsible for triggering the procedure, together with the care teams, at the moment specified in the request.

In the absence of family members involved in the advance request, appropriate authorities would provide a recourse mechanism to trigger the procedure. In Quebec, the public trustee, who is a party to the levels of care, could perform this role.

Thank you for your attention and I hope you are courageous enough to move this important matter forward with a full understanding of the issues.

The Joint Chair (Hon. Marc Garneau): Thank you, Dr. Boisvert.

We're now going to move on to the round of questions.

I'm going to turn the rest of the meeting over to the co-chair, Senator Martin.

[*English*]

The Joint Chair (Hon. Yonah Martin): Again, thank you to the witnesses.

We'll go to the first round of questions from the House.

Mr. Cooper, you have five minutes for your questions.

Mr. Michael Cooper: Thank you very much, Madam Co-Chair, and thank you to the witnesses.

I'm going to address my questions to Dr. Gallagher.

In the last panel, Dr. Downie said that it would be illogical not to extend advance requests—there are already advance requests in the context of MAID in some limited circumstances—that advance decisions, including those about the withdrawal of life-sustaining treatment and other medical interventions are already available to patients if they choose, and that the safeguards in place for those advance decisions could quite easily be adopted in the case of advance requests for MAID.

What are your comments on that, Dr. Gallagher? Could you expand on that?

Dr. Romayne Gallagher: Thank you very much for the question.

I heard that comment. I think there is a huge challenge because of things I mentioned in my commentary. We know from about 30 or 40 years of research into effective forecasting that people tend to think things will always be worse in the future than they actually will be. We also know that people adapt as well.

I think it's very different from saying, "I'm nearing the end of my life. I want assisted dying over the next few days, but, if I should lose my capability, these are my wishes." The average lifespan of people after a diagnosis of dementia is up to five years. In the case of the idea Dr. Downie mentioned—"If I don't recognize my family for two weeks, you can terminate my life"—how are we going to compel doctors to do this?

This is going to be an extremely challenging thing to work out. People change doctors, locations and provinces. This is going to be a nightmare, and I don't see how arranging a deal with one provider will last through a long trajectory of illness.

Mr. Michael Cooper: Dr. Downie seemed to present it as though it would be very easy: You would sit down and work out this arrangement, and you would discuss intolerable suffering. Of course, you're not experiencing that intolerable suffering, so you're discussing it beforehand, without living it. Somehow, however, according to Dr. Downie, this will result in a written request that will be able to speak for that patient without needing the guidance of a third party, because it could all be assessed objectively to determine whether or not the patient's wishes could be carried out.

What are your thoughts on that?

● (2105)

Dr. Romayne Gallagher: I think it would be incredibly challenging. My work in long-term care has taught me that usually people who arrive in long-term care will often last longer than you think. It will be more complicated than you think. Trying to make it out as a simple exchange between two people is bound to be complicated.

I think Dr. Ferrier, in the previous session, mentioned how complicated it gets with blended families, with people who have different ideas about wills, and so on. It really does complicate things, particularly when people have a previous strained relationship with the patient.

Mr. Michael Cooper: Thank you. I'm out of time.

The Joint Chair (Hon. Yonah Martin): You have about 20 seconds.

Mr. Michael Cooper: Is there anything else you'd like to add in those 20 seconds, Dr. Gallagher?

Dr. Romayne Gallagher: I was hoping someone would ask me, but I can't do it in 20 seconds.

It's about how we could improve palliative care because, through accreditation, we could expand standards and screening for distress throughout all chronic diseases. That is the way to enforce this: through accreditation. It would make a huge difference.

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

Next we have Mr. Maloney for five minutes.

Mr. James Maloney: Thank you, Madam Co-Chair.

Thank you to all of our witnesses. This is a challenging discussion, but it's one we must grapple with.

Dr. Gallagher, I'm going to ask you one question.

You started by saying that literature shows that people are poor at anticipating change. Is there any scenario in which you think advance requests for medical assistance in dying would be appropriate, or do you rule them out entirely?

Dr. Romayne Gallagher: I tend not to base things on one case or the rare case or things like that. I think we have to make policy that will manage for most Canadians. I often think, as we do in medical situations when we talk about benefits and risks, that it's very compelling to say, "Gosh, take me out of here." I used to think like that when I hadn't spent much time in long-term care. I'd just pop in, and I'd think, "Oh my God, this looks terrible", but when I worked there I found it was very different, so I—

Mr. James Maloney: Thank you, Dr. Gallagher. I don't mean to interrupt; it's just that I don't have much time.

The answer is no. Is part of that because it's your view that once people enter a certain state, they're not able to provide their consent?

Dr. Romayne Gallagher: It's partially because of that, but it's also because they may not have the same degree of suffering and they may have adapted to things. It's extremely hard for someone else to judge, particularly when people are unable to communicate as well as they used to.

Mr. James Maloney: I'm going to ask this question to the other two panellists.

In terms of consent, informed consent is a legal concept. It is designed to protect patients, but what we're talking about is real-life personal decisions that people have to make about their own health. My question is this: Would you not say that people can make an informed decision to request MAID, knowing that when it's time to be administered, they don't have the capacity to change their mind?

The Joint Chair (Hon. Yonah Martin): Dr. Thorpe, go first.

Dr. Lilian Thorpe: No, the longer the time is between a request and the actual event, the harder it is to anticipate how one feels and how one interacts with the world.

I think it's possible to have an informed consent when it's for a very short period of time, but the longer the time gets, the more you change. I think it would be very hard to have informed consent. I think this will become collaborative decision-making. I don't think it's as simple as just taking what somebody describes they might have wanted and what their suffering would be, then having everybody being able to act on it. I think it would be really complicated.

Mr. James Maloney: Dr. Boisvert, that's a good segue over to you because of that patient you described who has Alzheimer's.

Wouldn't she have been able to provide you with informed consent and not be in this situation she is now in the scenario I just put forward?

● (2110)

The Joint Chair (Hon. Yonah Martin): Go ahead, Dr. Boisvert.

[*Translation*]

Dr. Laurent Boisvert: When I met the patient, she was certainly fully capable of describing what she wanted to experience and what she did not. She was able to explain it clearly.

If the patient had been able to complete an advance request, we would have entered these details. The name of the proxy in the event of the patient's incapacity would also have been entered. This third party would have been responsible for triggering the procedure, meaning to go ahead with medical assistance in dying, in accordance with the criteria already specified by the patient when she was still capable of doing so. The care team, together with the third party, would look at the facts and the assessment, as Dr. Downie explained, and we would then proceed with medical assistance in dying.

[*English*]

Mr. James Maloney: In that scenario, then, Dr. Boisvert, who would make the decision with respect to whether or not the criteria had been met?

The Joint Chair (Hon. Yonah Martin): Dr. Boisvert, you have about 30 seconds.

[*Translation*]

Dr. Laurent Boisvert: The third party is part of the procedure and is aware of the criteria specified by the patient for triggering the procedure. However, it is up to the clinicians, meaning the two doctors, because we have continued with the same approach, to establish whether the criteria have been met and whether the request is admissible. The clinicians make the decision.

[*English*]

Mr. James Maloney: Thank you.

[*Translation*]

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

[*English*]

Next we'll have Monsieur Thériault for five minutes.

[*Translation*]

Mr. Luc Thériault: Dr. Boisvert, thank you for having presented these two cases.

They clearly illustrate the situations that patients and doctors encounter.

Some witnesses told us that it was virtually impossible to have informed judgment when the goal is to make a decision several years in advance.

What's your view of this?

Dr. Laurent Boisvert: I don't think it's virtually impossible for people who are capable, who are aware of the situation in which they are making the decision, and who know the reasons why they are making that decision.

They need to specify the criteria and the clinical circumstances that will determine when it will happen. People go through this process in a free and informed way, knowing full well where things are headed.

Mr. Luc Thériault: Is a prior diagnosis essential, Dr. Boisvert?

Dr. Laurent Boisvert: I fully agree with Dr. Downie on this. An advance request for medical assistance in dying should only be possible once the patient has had a confirmed diagnosis of neurocognitive disorders or dementia that will definitely be harmful to the patient's capacity as time goes by. So a diagnosis must have been confirmed for a person to be able to make an advance request.

Mr. Luc Thériault: Are requests for medical assistance in dying strictly limited to cases of degenerative neurocognitive diseases?

Dr. Laurent Boisvert: Advance requests are made essentially because the patients know they are going to lose their ability to express their wishes one day or another because of their illness. And yes, it's for degenerative neurocognitive disorders.

However, other diagnoses may be involved. Let's, for example, look at Parkinson's disease, which is a degenerative neurological disorder, but can lead to cognitive problems. It's much less frequent in cases of amyotrophic lateral sclerosis and multiple sclerosis, which generally do not have a cognitive impact on patients.

Mr. Luc Thériault: So it could not cover things like strokes or aneurysms, which could create a disability or incapacity.

Could these medical issues be addressed by means of advance medical directives?

Dr. Laurent Boisvert: Healthy people would not be able to say that they would like to have medical assistance in dying if they were to have a stroke.

Mr. Luc Thériault: At the moment, people can make an advance medical request to specify, for example, that they do not want to be resuscitated if they have a stroke or cardiac arrest. People might wish to avoid the risk of sequelae stemming from such an event.

That exists already, doesn't it?

● (2115)

Dr. Laurent Boisvert: Advance medical directives in Quebec already cover cases like that. However, the mechanism is completely different, because the person is asking not to receive treatment.

For an advance request for medical assistance in dying, they are instead asking to receive this assistance once certain conditions have been met.

Mr. Luc Thériault: As soon as a patient is in a terminal phase, whether because they are suffering from Alzheimer's disease or dementia, and are curled up on their bed, could we consider that palliative care, which is after all a form of care, is a form of aggressive therapy because we would not be complying with the patient's request, and not doing what they have asked for?

Dr. Laurent Boisvert: Are you asking about a case in which the patient has made an advance request for medical assistance in dying and where we did not provide it?

Mr. Luc Thériault: Yes, that's right.

Dr. Laurent Boisvert: In a case like that, it would be more than a matter of aggressive therapy. As I mentioned earlier in discussing measures, measures are not necessarily safeguards. The advance request for medical assistance in dying is binding and cannot be challenged. If we were not to comply, that would be more than aggressive therapy.

Mr. Luc Thériault: So the fact that it is binding is crucial.

Dr. Laurent Boisvert: It's crucial.

Mr. Luc Thériault: Some witnesses have said that when they explained the various options available to their patients, the patients did not opt for solutions like advance requests.

What's your view of that?

[*English*]

The Joint Chair (Hon. Yonah Martin): Thank you. We have run out of time for that question.

Next we'll have Mr. MacGregor for five minutes.

[*Translation*]

Mr. Luc Thériault: I was alluding to medical paternalism.

[*English*]

Mr. Alistair MacGregor: Thank you, Madam Co-Chair.

We heard from Dr. Gallagher in her opening statement that people are poor at anticipating what future medical conditions are like. Many witnesses have talked about the difficulty in determining consent.

Dr. Thorpe, our committee hasn't yet had your submission distributed to us, but we will look forward to reading it in detail. I appreciate your submitting it to our committee.

In your opening remarks, you urged our committee to really think very clearly about the guidelines that need to be set up, because people change and in some cases adapt to their new medical realities.

From a practical point of view in terms of what our committee may make recommendations on, if we permit advance requests for medical assistance in dying, for you as a practitioner, how often would you want to see someone be legislatively required to revisit their advance requests so that we can be sure that...? Is it every year, every couple of years, every three years? I don't know.

Is this something that we as a committee need to be checking in on so that people are being required to look at their advance requests to be sure this is something that they still want as time goes forward?

Dr. Lilian Thorpe: Thanks. That's a good question.

I think it depends on what's wrong with a person. If we go with Jocelyn's idea that we only have these for someone who's had a diagnosis, if somebody has had a diagnosis of dementia, then they probably need to redo this every year, because they will have decline every year, and I think it should be done.

If one didn't have the requirement for having a diagnosis, which I actually wouldn't rule out.... I think some people have a family history of very severe dementia, and they might want to indicate what they would wish at, say, a chronic vegetative state. That might be a very different thing. That might be a five-year thing, but once one has a chronically degenerative condition, very frequently.... It's even quicker if you have something like Creutzfeldt-Jakob disease, which is very fast and progressive. I think there are a lot of these very context-specific things that we have to think very hard about.

I don't think it's not doable, and I'm not saying that we shouldn't have advance requests; I'm just saying that we have to really think about this and think about the practicalities for those of us who are going to end up seeing someone walking around not knowing their family members but still enjoying life. How are we going to do this? Are we going to hold them down? I can't see any of us doing this.

● (2120)

Mr. Alistair MacGregor: Would you, as a physician, appreciate a standardized type of request, specifying the bare minimum amount of detail that is required on a form and that also has to be accompanied by a personal note to better fill in the blanks that the form may present? Can you elaborate a bit more on that specific part?

Dr. Lilian Thorpe: Absolutely, and you know what? Jocelyn talked about that. It's going to be really important to have exactly what that person's wishes are at that time.

It's also important to have that person meet with an informed person, a physician or a nurse, who knows what dementia looks like, and to have it documented that the person actually did have a full understanding of what they were talking about at the time. It may be that they may not fully understand what happens in 20 years, but at least we have some idea that they had a discussion with someone to think through all the issues. I think people very frequently sign things they don't understand. It's very common.

Mr. Alistair MacGregor: On that concept of fully knowing what dementia looks like, we've often heard during this committee about the stigma that many people have—i.e., “Oh, my goodness, if I were to were to get a diagnosis of Alzheimer's, my life would essentially be over.” They look at the state of long-term care in Canada, and there's a very real fear there.

In your conversations, what have those been like for you in a practical sense, dealing with those very real questions and fears that people have?

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

Dr. Lilian Thorpe: We talk about dementia always being terrible, but it's not always. We have people in our good nursing homes who are singing and dancing along. They can't recognize the families, but they're still having some quality of life. It's not what they anticipated, but they're still having quality of life. Those are the good ones.

We need to improve palliative care and long-term care facilities, absolutely, with more person-centred care, absolutely.

Mr. Alistair MacGregor: Thank you.

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

I'll turn this back to our co-chair for questions from the senators.

The Joint Chair (Hon. Marc Garneau): Thank you, Senator Martin.

With that, we'll begin with Senator Kutcher. These are three-minute rounds.

Go ahead, Senator.

Hon. Stan Kutcher: Thank you very much, Chair.

I'm going to share with you a case that I know. I'd like to hear from Dr. Boisvert and Dr. Thorpe on this.

Here's a person with stage 7 dementia. They are unable to self-toilet. They smear their feces on the wall or eat them. They do not recognize their family. They fall unless they're tied on to a chair. They can't eat solids because of the fear of choking. However, they get very good care. Every time they're dirty or soiled, they get cleaned up. They get dressed up. They spend their whole day sitting in front of a television set, laughing and singing, clapping at TV shows, and moving their body in time to the music.

Is the person suffering? How do you know if the person is suffering? If they had given you an advance request saying, “If I'm in this condition, I would like to have MAID”, would that assist you in that decision-making?

The Joint Chair (Hon. Marc Garneau): Dr. Thorpe, do you want to start with that?

Dr. Lilian Thorpe: It would certainly to help me to know what their thoughts were to start with, but I also don't think that the person would be able to necessarily predict whether they were suffering or not, because they're not there. That person does change. It's a person whose whole personal, emotional and physical experience does change.

It's a terrible care state to be in. At that point, what do you do? The practicalities will be really difficult. When somebody's this far gone, using supportive end-of-life comfort care measures might be much easier to institute than actively getting medications into that person, who is often, as I said before, not even taking in their drugs anymore. They're not even eating much anymore.

I still think this is going to be a difficult situation. There will be some situations—I've had patients with dementia who've had MAID—that will be doable, but many, like this one, will be very difficult for everyone involved, for the family members, the caregivers and the providers.

[*Translation*]

The Joint Chair (Hon. Marc Garneau): Dr. Boisvert, would you like to add anything?

Dr. Laurent Boisvert: Yes, certainly.

If that patient has completed an advance request for medical assistance in dying to avoid being in the kind of situation you described, then that patient is certainly suffering. If the conditions have been specified and the patient has reached that point, then we go ahead with medical assistance in dying, in accordance with that patient's wishes as specified in the advance request.

No one can say that patients, just because they can bop in time to the music, are happy. There is no such thing as a happy form of dementia; dementia exists and manifests itself in different ways. A person who was capable at the time they specified details in their advance request and who gave their free and informed consent does not want to experience that kind of situation.

● (2125)

The Joint Chair (Hon. Marc Garneau): Thank you, Dr. Boisvert.

I'm now going to give the floor to Senator Mégie for three minutes.

Hon. Marie-Françoise Mégie: Thank you, Mr. Chair.

Thank you to the witnesses.

My first question is for Dr. Boisvert.

I'd like you to tell us more in connection with your answer to Mr. Thériault about the refusal to administer medical assistance in dying to a patient who had requested it.

And if an advance request had been authorized, what obstacles might have complicated the provision of medical assistance in dying, in your opinion?

Dr. Laurent Boisvert: For your first question, about refusing to give medical assistance in dying, I'll just repeat that it's against the code of ethics to refuse to administer medical assistance in dying to a patient who has requested it, and who, in the assessment by practitioners, meets the eligibility criteria.

Currently, some people are not complying with their code of ethics with respect to medical assistance in dying. These people might behave in the same way with respect to advance requests. I can't tell you any more than that. Strictly speaking, it would be against the law if the Criminal Code were to include provisions establishing procedures that could be applied with respect to medical assistance in dying.

The second question, I believe, was about what appears to be a difficult issue.

Hon. Marie-Françoise Mégie: I'd like to know what could constitute a barrier to the provision of medical assistance in dying.

Dr. Laurent Boisvert: At the moment, we do not provide medical assistance in dying to all types of patients. And you can be sure that not all doctors or nurse practitioners in other provinces will administer medical assistance in dying when there have been advance requests.

Situations like this are not easy, because you're dealing with someone who is no longer the same person as the one who completed an advance request. It is indeed a completely different person, one whose billions of neurons have been destroyed by dementia or by the disease. It's no longer the same person.

The disease can manifest itself in different ways. People can become aggressive, or as Senator Kutcher described, move in time to the music. In any event, medical assistance in dying will be provided to them because that's what they wanted. It will not necessarily be easy, but it can be carried out in a manner that is perfectly correct.

Hon. Marie-Françoise Mégie: Do I have a few seconds left, Mr. Chair?

The Joint Chair (Hon. Marc Garneau): You have only 10 seconds, so I think we'll move on to the next person.

Thank you, Senator Mégie.

[*English*]

Senator Wallin, it's over to you for three minutes.

Hon. Pamela Wallin: Thank you very much.

I have two questions for Dr. Thorpe.

We come from the same part of the world, which is Saskatchewan. I want to ask about the rural-urban issue and access.

Presuming that the pandemic has given everybody some experience with this, are you now comfortable doing assessments on Zoom or some other kind of technology? Does that actually create more access because people don't have to travel and you can do it more often?

Dr. Lilian Thorpe: Thanks. That's a good question.

Saskatchewan actually has a centralized MAID program. We have really good access throughout the province. We have people in most areas of the province. There is now funding for the assessors and providers to go out, and their time is reimbursed.

Some of the assessments are done virtually. We're all better at that now, but we like to have at least one of the assessments in person. We have generally been able to have a really quick response. We probably have one of the quickest responses across the country. It's usually within a week, and often much quicker.

Certainly we've learned assessment by virtual means. The second assessment is sometimes easier to do in a virtual format. I have done quite a few of those, as I'd see most of the more complex cases. There's been some improvement with this, but I prefer to see them myself.

● (2130)

Hon. Pamela Wallin: Thank you.

On my second question, we've heard statements about this over the course of our hearings. As a long-time MAID assessor, do you know of any cases of forced MAID—of a practitioner or a family member compelling someone, clearly against their will, to subject themselves to MAID?

Dr. Lilian Thorpe: Absolutely not. What I see much more often is that family members dissuade their families from having MAID. That is much more common.

I've never seen a case of anybody pushing someone into MAID. You need two assessors, and with two separate assessments, you would absolutely be aware of that pressure.

Hon. Pamela Wallin: The safeguards are in place.

Dr. Lilian Thorpe: I think so, yes.

Hon. Pamela Wallin: Thank you very much.

The Joint Chair (Hon. Marc Garneau): Thank you.

[*Translation*]

Go ahead, Senator Dalphond.

Hon. Pierre Dalphond: Thank you, Mr. Chair.

Dr. Boisvert, my question is for you.

Based on your experience and your area of specialization, can you tell me whether, since the act was amended, you have encountered any situations in which patients, out of fear of losing capacity and being unable to consent later, decided to advance the date on which they would receive medical assistance in dying, and perhaps miss out on six months or a year of happy living, simply because they wanted to make sure they could decide when their life would end?

Dr. Laurent Boisvert: I have in fact given medical assistance in dying to several patients with dementia who clearly retained their capacity until the last minute, but who would definitely have liked to spend a little more time with their family. If they had been able to make an advance request, the criteria they would have chosen would have been not being able to care for themselves or recognize their family members, which would have left them quite a lot of additional time. It can indeed take months and sometimes even years in some instances before reaching that state.

I think people have heard about the case involving Ms. Demontigny, who is fighting for advance requests. She is fighting for the additional years she might have.

I have indeed had patients who received medical assistance in dying too soon, as it were, because they did not have the opportunity to complete an advance request.

Hon. Pierre Dalphond: , People are being deprived of their decision to live for additional months or years, because they are forced to choose to die now in order to be able to exercise their decision.

Dr. Laurent Boisvert: Absolutely.

Hon. Pierre Dalphond: Thank you, Dr. Boisvert.

The Joint Chair (Hon. Marc Garneau): Thank you.

[*English*]

Now we'll go to Senator Martin.

Senator Martin, you have three minutes.

The Joint Chair (Hon. Yonah Martin): Thank you, Chair. My question is to Dr. Gallagher.

Based on your experience and knowledge, what do you see are the major risks of advance care planning that includes MAID? What should we be aware of?

Dr. Romayne Gallagher: Well, I think you should be aware of the extreme difficulties in actually deciding when and how to do this. I think there's little evidence that shows that doing it this way or that way, or defining some kind of arrangement between two people, will sort out the problems.

Life is difficult, and things don't always work out the way that one plans. I think it's knowing, as Dr. Thorpe very ably pointed out, that life is complicated and things are challenging, and it's not easy to do this.

There are a lot of risks, and the benefits are hard to measure, so I do not believe it's in the best interest to enact this kind of legislation. I think it's very problematic.

The Joint Chair (Hon. Yonah Martin): In the time that I have remaining, would you like to talk a little bit more about what the federal government should do regarding palliative care?

Dr. Romayne Gallagher: Oh, thank you.

What we want to do is to have a system where you....

We know that all provinces have to rely on accreditation of their organizations. Therefore, you can put in place standards and measures of the quality of palliative care. You can also enact symptom screening and distress screening in all chronic disease clinics.

I believe that doctors have great intentions, but they often aren't focused on symptoms; they're focused on disease indices and testing and so on. We need to hear from people. People will often rate very differently on a survey than what they will admit to their family doctors. We need to pick up suffering early. We need to have a system in place that ensures we are detecting it and addressing it early, before people are suffering to the point where they say, “My life is intolerable the way it is right now.”

It's my hope, knowing that this is within the control of the federal government, that in your role in reviewing the state of palliative care, you will take this incredible step to enforce a change in our system that will benefit everybody, no matter whether they have MAID or they have a natural death. I think it's very important.

I thank you.

● (2135)

The Joint Chair (Hon. Marc Garneau): Thank you very much.

I'd like to thank Dr. Gallagher and Dr. Thorpe.

[*Translation*]

And I'd also like to thank Dr. Laurent Boisvert.

Thank you for having testified this evening and answering our questions on an important, but very complex subject. We are truly very grateful. I'd like to thank everyone for having remained available at such a late hour, especially for those of you who live in the eastern part of the country.

[*English*]

Thank you very much. We very much appreciate your being with us this evening.

With that, I will remind the committee members that our next meeting is one week from today. It will be a three-hour meeting. As agreed upon at the beginning, we will reserve the third hour for in camera committee business.

Before we adjourn, there has been a suggestion that we extend the period for people to provide briefs, given the fact that our final report has been extended to October. I'd like to see a show of hands from people supporting allowing briefs to be presented up until May 30.

Does anyone have a problem with that?

I can't see everybody in the room, but I'm looking at—

The Joint Chair (Hon. Yonah Martin): There are lots of thumbs up. Everyone's thumb is up.

The Joint Chair (Hon. Marc Garneau): Yes. There are lots of thumbs up.

That sounds very good. We will notify people that they can provide briefs—the length is still 1,000 words—up until May 30.

Thank you very much.

This meeting is now adjourned.

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