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Co-Chairs:
The Honourable Marc Garneau The Honourable Yonah Martin



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• (1830)

[English]

The Joint Chair (Hon. Marc Garneau (Notre-Dame-de-Grâce—Westmount, Lib.)): I will now call this meeting to order.

I would like to welcome our witnesses for this evening's session as we continue our statutory review of the provisions to the Criminal Code relating to medical assistance in dying and their application.

Tonight we have the pleasure in the first panel of having Dr. Raphael Cohen-Almagor, professor of politics at the University of Hull, as well as Mr. Pierre Deschamps, who is a lawyer and ethicist. We also have two people from Dying with Dignity Canada: the Hon. James Cowan, member of the board of directors and a former Canadian senator, and Helen Long, chief executive officer.

There are a few quick rules.

[Translation]

First of all, I know everyone appreciates the health measures that were put in place during the COVID-19 pandemic. I would ask all those in the committee room to adhere to those rules.

[English]

With respect to our members and panellists this evening, there are a few small details. You may speak in the official language of your choice—English or French—and we have translation. If there are problems for you in hearing the translation, please let us know. We'll suspend and fix the problem before we get going.

Second, please don't speak until I give you the authorization to speak. If you wish to draw my attention to something, there is the "raise hand" feature on Zoom. You can use that. When you speak, please speak slowly and clearly.

The way we'll proceed is we will begin the evening with the three panellists each speaking for five minutes, and then we will follow that with a question period.

We'll get the show under way. Dr. Cohen-Almagor, if you are ready, the microphone is yours for the next five minutes.

Dr. Raphael Cohen-Almagor (Professor of Politics, University of Hull, As an Individual): Good afternoon, good evening. Thank you for your invitation to present my views on end of life today.

My name is Raphael Cohen-Almagor. For more than 30 years, I've been studying end-of-life concerns.

Ethically speaking, I think patients should be able to receive medical aid to end their lives. This should be done in the most attentive and careful way.

I restrict my reasoning to autonomous patients who are able to decide for themselves. Incompetent patients are, by definition, not autonomous. As they're unable to decide for themselves, the road for potential abuse is wider.

During the past decades I served as a consultant to several legislatures on end-of-life treatment. *Inter alia*, I served on the public committee that legislated the Dying Patient Law in Israel. I submitted to you the specific section of the law that addresses advance directives.

Advance directives are problematic. They're often made without the opportunities for full informed consent. On what basis did a patient make the decision that she would not want to be treated? A decision not to receive treatment should be based on a clear understanding of the situation. It is essential that a patient understands the disorder, the available alternatives and her chances and risks. This can be rather complicated when the physicians themselves do not have a clear picture about the condition and cannot provide a reliable prognosis.

My research in nine countries—the United Kingdom, Canada, Israel, the United States, Australia, New Zealand, the Netherlands, Belgium and Switzerland—shows that there have been a number of cases in which a physician playing God has abused their position of authority to make decisions that are not in the patient's best interests. Also, end-of-life care is often compromised due to economic considerations and a shortage of resources.

Research has evidence that advance directives are often made without an opportunity for full informed consent. For example, in the United States, advance directives might be utilized by medics against the patient's best interests to save costly resources. The research shows that advance directives have not fulfilled their promise of facilitating decisions about end-of-life care for incompetent patients. Many legal requirements and restrictions concerning advance directives are counterproductive. Despite their benevolent intentions, they have created unintended negative consequences against patients' wishes.

Let us examine the highly problematic case of dementia. As you may know, medicine at this point has not fully deciphered the mysteries of the brain. We know a lot about the heart, about the lungs, about the kidneys and about other organs, but we are yet to fully understand the brain. The human brain is struggling to understand the brain. Therefore, caution is a must.

In the first stage of dementia, patients tend to suffer from fears of becoming a burden on loved ones and on their medical care, as well as losing their independence and dignity. The suffering is mental. The suffering can be alleviated with dualistic palliative care that addresses the patient's mental, psychological, physical and social needs with assurances that the patients have an intrinsic value notwithstanding their deteriorating current condition, with family solidarity and with compassion and respect for the patients who are now at a junction where they need attention more than ever before.

As patients with dementia tend to be older adults, they should be assured that it is payback time. All their lives, they gave to others—their children, their friends, their society. Now it is their turn to receive. The moral imperative is to provide compassion and care for people with dementia.

With the advance of dementia, its distressing symptoms become more frequent. Pain and agitation become more common as death comes nearer, but generally speaking, these are treatable symptoms. Studies have shown that cognitive behavioural therapy, palliative care and hospice care could greatly improve the care of patients with advanced dementia. Patients with dementia who receive hospice care have fewer hospitalizations and milder psychiatric symptoms as compared with those who did not receive hospice care. Furthermore, families of patients with dementia who receive hospice care report greater satisfaction with care. When individuals are aware of the complexities of dementia and factor in the contradiction at the end of life whereby, with severe dementia, they will not be able to remember their previous wish and may well be pursuing other interests, yet are making a conscious decision that this is the time when their own lives should be terminated, that decision is bound to be fraught with doubts.

• (1835)

At the onset of the illness, death is premature. In the later stages, it is questionable because the patients show that some aspects of life are still meaningful to them. In the last stage, the patients are no longer autonomous to make such momentous decisions, and the physicians cannot be sure what the patients then want.

The dementia paradox cannot be solved with euthanasia. It needs to be addressed by more care, compassion and good doctoring. The medical team has a crucial part to play in promoting quality of care, from diagnosis until the last stages of dementia, to assess changes in cognitive functioning, memory, depression, fears, communication difficulties and behaviour alongside identification and treatment of symptoms. Early requests to die are often the result of desperation that the medical staff and the patient's beloved people can forestall by providing them outstanding support, care and sharing that will assure the patients that they are and will remain members of the human community. What we should do—

The Joint Chair (Hon. Marc Garneau): Doctor, I'll ask you to wrap up now.

Dr. Raphael Cohen-Almagor: Yes.

What we should do is humanize care for the living.

The liberal state has an obligation to protect all people, especially the vulnerable. To resolve the conflict between past competent and current incompetent interests, it is suggested that instead of

simply enforcing all prior directives, doctors, families, and other people involved in the care of incompetent patients should be able to examine whether the patient's interest would be best served by actions contrary to advanced directives. What is required is a careful study, accumulation of knowledge and data, addressing concerns, learning from mistakes and attempting to correct them before rushing in a frenzied fashion to introduce more liberal ways to euthanize patients. Haste makes waste.

Thank you very much.

• (1840)

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

[*Translation*]

I now give the floor to Pierre Deschamps for five minutes.

Mr. Pierre Deschamps (Lawyer and Ethicist, As an Individual): Good evening, everyone.

Thank you for inviting me to testify.

This evening I will be discussing advance requests for medical assistance in dying.

Advance requests for medical assistance in dying make it possible for capable persons to consent in advance to the provision of medical assistance in dying where they are in a state of life or health incompatible with their values, such as a state of advanced dementia preventing them from recognizing family members or from performing their activities of everyday life. Such requests are now made as part of a relaxing of the rules governing access to medical assistance in dying, as may be seen in the way Canadian legislation has evolved on the matter.

I would like to draw your attention to a few historical facts.

Bill C-14 made it possible for persons to agree to have a physician or nurse practitioner inflict death on them with their consent, provided they gave their consent at the time the medical assistance in dying was administered. This constituted an exception to, or a derogation from, the rule stated in section 14 of the Criminal Code that prohibits a third party from inflicting death on a person even where that person has given consent. This development was accompanied by the legislator's introduction of safeguards that restricted or limited the circumstances in which medical assistance in dying may be provided based on the eligibility criteria developed at that time.

Bill C-7 added an exception to that rule by permitting persons to receive medical assistance in dying even if, at the time it is administered, those persons are unable to consent to it, provided they have signed a prior written agreement with a physician waiving the requirement to consent to medical assistance in dying at the time it is provided. Here again, the legislator established safeguards to protect the person who is to receive medical assistance in dying.

It is now being proposed that persons who do not yet have a grievous and irremediable medical condition, but who anticipate having such a condition, should, if in a given situation such as a state of advanced dementia preventing them from recognizing family members or performing their activities of everyday life, be allowed to receive medical assistance in dying in circumstances in which — and I want to emphasize this — they, although conscious, are unable to consent to the provision of medical assistance in dying.

By legislating on this matter, Canada would be joining a very small number of countries that have accepted that a person may receive medical assistance in dying by means of an advance request. I am referring to the Netherlands and Belgium, which have very different statutes on this issue.

In the Netherlands, advance requests for medical assistance in dying are authorized, but, between 2017 and 2019, there were only two or three cases per year of persons suffering from advanced dementia who received euthanasia in accordance with their advance medical directives.

In Belgium, an advance euthanasia directive takes effect only if a person is irreversibly unconscious at the time of euthanasia. In other words, that person must be in an irreversible coma. From 2016 to 2020, between 22 and 33 persons per year received euthanasia in accordance with their advance medical directives.

Unlike Belgium, Canada is currently considering the possibility of providing medical assistance in dying to a person who has made an advance request, not where that individual is in an irreversible coma, which presupposes a total loss of consciousness, but where a person with a grievous and irremediable medical condition such as advanced dementia is still conscious, even if only minimally so, but incapable of giving free and informed consent to the provision of medical assistance in dying.

In such circumstances, Parliament would be asked to validate or sanction under criminal law the possibility for a person who makes an advance request for medical assistance in dying to receive such assistance if the conditions that individual has established as activation triggers of his declaration are met.

● (1845)

While the drafting of an advance request for medical assistance in dying entails its own difficulties, particularly with regard to the identification of factors that may determine when it should take effect, activation of the declaration presents challenges in many areas: the medical condition required for consideration to be given to providing such assistance; the provision of medical assistance in dying to an incapable or more or less unconscious person; the severity of the person's cognitive losses; the family members who would be called upon to commence the assessment process leading to the provision of medical assistance in dying; and the medical and other assessments required to determine whether the person has reached a point where his or her previously expressed wishes must be considered.

Here the challenge for legislators is to design robust safeguards that will protect persons who have made advance requests for medical assistance in dying — such requests are generally made many

years before the condition that may potentially give rise to their activation appears — from abuses such as medical assistance in dying that is provided too early or in haste under pressure from family members or medical staff who sympathize with the state of mental deterioration of the person, who will thus be put in a highly vulnerable position.

In addition to Parliament's intervention in criminal law, there can be no doubt that provincial statutes, as in Quebec's case, will be required to determine the circumstances in which an advance request for medical assistance in dying may be activated when a person is considered incapable of giving consent yet is still conscious, even if minimally so.

The Joint Chair (Hon. Marc Garneau): Mr. Deschamps, I'll ask you to conclude your presentation, please.

Mr. Pierre Deschamps: Federal and provincial statutes should ideally be harmonized, if that were to prove necessary.

In conclusion, developments in Canadian legislation on medical assistance in dying are consistent with the perspective of long-term recognition of the fundamental right of every human being to choose when and how to die with the assistance of a third party, that is, a physician or other health professional.

Although that right is not formally acknowledged or entrenched in the Canadian Charter of Rights and Freedoms, it is hinted at in connection with a number of rights and freedoms.

For the time being, the exercise of that right is tempered by various safeguards that constitute so many limitations on the full exercise of that right. This includes the requirement that a person have a grievous and irremediable medical condition, be in constant, intolerable and incurable suffering, exhibit advanced and irreversible decline in capacities, be of adult age and have the capacity to give or waive consent.

Thank you for listening.

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

[*English*]

We'll now go to Senator Jim Cowan and/or Ms. Long. I don't know if you're going to share the speaking, but you have five minutes between the two of you.

Please go ahead.

Ms. Helen Long (Chief Executive Officer, Dying with Dignity Canada): Thank you. We will be sharing our time.

Dying With Dignity Canada, or DWDC, is a national human rights charity, which has been committed for the past 42 years to protecting end-of-life rights and helping Canadians avoid unwanted suffering. For Canadians, this is not an academic debate. It is about compassion, avoiding suffering and fundamental rights.

Every day we hear from individuals and families as they navigate end-of-life choice, including but not limited to medical assistance in dying, or MAID. In developing our position, we sought out the insights and lived experience of health care practitioners, individuals with physical disabilities and mental disorders, first-person advocates and other volunteers within the MAID community.

We believe that everyone should have both the right to live and the right to choose their end of life. We encourage the government to continue to invest in increasing access to palliative care and in providing additional supports for people living with disabilities and mental disorders. At the same time, we strongly support the statement made by Dr. Stefanie Green last week that MAID and community resources for mental health, palliative care and disability supports be developed and supported in parallel.

By far, the most frequently asked questions we receive are those related to advance requests for MAID. An advance request involves a competent person making a written request that could be honoured later, after they lose the capacity to make medical decisions for themselves. It would allow an individual to describe in writing a future state in which they would like to access MAID.

We know, through multiple Ipsos polls, that Canadians support advance requests. Those results have been consistent over time and in line with those from the government consultation in the spring of 2020. Ipsos polling in April of 2022 indicated that 85% of Canadians support an advance request for those diagnosed with a grievous and irremediable condition and 77% of Canadians support an advance request without a diagnosis.

Canadians tell us that they are concerned about their capacity to provide informed consent to MAID due to a family history of neurocognitive conditions, such as dementia or Parkinson's, or that an accident or other medical problem could result in diminished mental capacity. Advance requests for MAID would allow those who so choose to avoid a life of grievous and irremediable pain and suffering if loss of capacity occurs.

DWDC believes that advance requests should be allowed with or without a diagnosis of a serious and incurable illness. Canadians already have the right to provide advance direction regarding treatment options through personal care directives. The same right for an advance request for MAID would allow those who anticipate a loss of capacity to ensure that the guiding principles of their lives are respected when they can no longer speak for themselves.

Senator Cowan will complete our statement.

● (1850)

Hon. James S. Cowan (Member of the Board of Directors and Former Senator, Dying with Dignity Canada): Thank you, Helen.

Our MAID laws have been driven and inspired by Canadians whose desire for dignity, autonomy and self-determination have led them to fight for the right to make decisions that align with their own personal values. These are people like Sue Rodriguez, Kay Carter, Gloria Taylor, Audrey Parker, Jean Truchon and Nicole Gladu. Today, we hear from people like Pamela Cross, Katherine Hammond and the Eusanio sisters, whose experience with capacity-eroding conditions motivate them to speak up and support changes to the law.

DWDC recommends that the assessment of eligibility for MAID, including the requirement of intolerable suffering as described in the advance request, be completed by health care practitioners when made aware of an advance request prepared previously by an individual who has since lost capacity. The advance request should

be documented in a manner that is consistent with the current process and include a personal statement that outlines the values and interests that are central to the person's life and the core of their identity. That statement must be considered by the practitioners when making their assessment.

Time does not allow us to go through the details of the careful safeguards we have outlined in our brief, which will be filed with the committee, but we invite you to review them in detail and we would be happy to expand on them and answer any questions.

Some clinicians have pointed out that individuals who have lost capacity and reach the point of what their advance request describes as suffering that is intolerable to them may not appear to be suffering at that time. However, the purpose of the advance request for MAID is to respect the previously expressed wishes of the person when they were competent. The safeguards and decision-making process ensure that the individual meets the criteria for assisted dying, and MAID would not proceed if the individual exhibits conscious indication of resistance or refusal.

There is no evidence that access to MAID in Canada or in any other jurisdiction has had a negative impact on societal values pertaining to individuals with capacity loss. Rather, it has brought more attention to end-of-life care in general, including palliative care, and to the need to ensure that all citizens can live and die well.

Thanks for your time today. We would be happy to answer any questions.

The Joint Chair (Hon. Marc Garneau): Thank you, Senator Cowan and Ms. Long.

That concludes our opening statements. We'll now go to a round of questions, and I will hand this over to my co-chair, Senator Martin.

The Joint Chair (Hon. Yonah Martin (Senator, British Columbia, C)): Thank you, Mr. Garneau, and thank you to all of our witnesses.

For our first round, we will begin with Mr. Cooper for five minutes.

I will give a 30-second warning, although I know that in the room you can see the time clock as a double-check.

Mr. Cooper, the floor is yours.

Mr. Michael Cooper (St. Albert—Edmonton, CPC): Thank you, Madam Co-Chair. I'm going to direct my questions to Professor Cohen-Almagor.

Professor, can you speak to the difference between an advance directive in the context of MAID versus an advance directive in terms of withholding life-saving treatment? If you can have the latter, why would you not provide for the former?

• (1855)

The Joint Chair (Hon. Yonah Martin): Is that for Dr. Cohen-Almagor?

Mr. Michael Cooper: It is.

Dr. Raphael Cohen-Almagor: I want to say something general about advance directives for competent patients and for incompetent patients. I studied this in nine countries, including Canada, although I was last in Canada in the early 2000s, so I haven't been here in the past 10 years or so.

In my studies, you can see time and time again that doctors who deal with dementia patients tell you time and time again that it might be the case that when a person in a certain situation comes to their end of life, knowing that they're going to end up not recognizing their own life, their relatives and so on, they change their mind. They find it meaningful and esoteric. They've now found meaning in something that would have been utterly meaningless to them, say, a few years ago.

I think you have to differentiate between conditions. If it's physical deterioration—a physical condition in which the mental capacity remains—I totally agree with James Cowan and Helen Long in all they said. When it comes to dementia and issues of the brain, I cannot agree, because people change and people change their minds.

Look at marriage. Many people, when they get married, think that marriage is for life, yet we see that 50% of the population get divorced. They change their minds. If you ask a young person whether he or she can perceive life in a wheelchair, the common answer is, "I'd rather die." God forbid they enter into that state after a car accident, but when they find themselves in a wheelchair, they don't want to die. The majority of them want to continue living. I've seen patients in horrendous conditions, but when you ask them, "Would you like to die?", they are silent.

We have to be very cautious when it comes to incompetent patients. To me, the issue of autonomy is something that we are all concerned about. I think all Canadians are concerned about autonomy. That's what motivates MAID: the autonomy of the patient. I don't think we can encompass that to incompetent patients. This is where we have to set the boundary, and the boundary should be very strong and very firm.

If you're going to pass these measures, we are going to open the gate to abuse, and Canada does not want that.

Mr. Michael Cooper: Thank you for that.

Can you speak to your work in other countries and some of the issues that you saw surrounding advance directives that you believe are a cause for concern?

Dr. Raphael Cohen-Almagor: I've spent a lot of time in Belgium and in the Netherlands. In the Netherlands, I saw advance directives of, let's say, something like "I would like to die if I don't recognize my children anymore." This is a statement made by a competent patient with a sane mind and so on, but God forbid it comes to the later stages. Of course, it doesn't hold any water—

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

Dr. Raphael Cohen-Almagor: —and, of course, nobody is going to take this seriously.

I went to a nursing home in Amsterdam and spoke with Dr. Bert Keizer, who wrote a very famous book, *Dancing With Mr. D*. Bert supports euthanasia for patients, but he finds it very difficult to support it for patients with dementia because he understands what it means. People change their minds, and you can't kill someone who sees that there's something meaningful, like watching television—

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

Next we have Dr. Fry for five minutes.

• (1900)

Hon. Hedy Fry (Vancouver Centre, Lib.): Thank you very much.

This is a very interesting, and a very charged set of circumstances. As far as I am concerned, having been a practising physician for 22 years, the idea of an advance directive is that the patient, as you said, should have informed consent, and then the patient should make a decision. If patients are ever going to come to a time when they are not *compos mentis*, they decide on the conditions that they wish to happen if and when they get there. That's what an advance directive is about.

The Supreme Court was very clear about section 7 of the charter, and then I wonder, because I hear you and Monsieur Deschamps. Does Monsieur Deschamps agree with the Supreme Court decision in Carter under section 7? Do you, sir, believe that a physician should second-guess a patient?

Patients are concerned that there will come a time when other people will do things to them. They are abused. Do you not agree that this abuse can work both ways? It can occur when a patient is not *compos mentis* and a family would like to get rid of the patient. If the patient in an advance directive says, "I don't care what happens to me; I would like to continue living", families could in fact make a decision with a physician that that's not so.

Similarly, families could make a decision with a patient who said, "There comes a time when I will not be able to mentally make a decision, and I want to be able to die with a certain amount of dignity, and here are my conditions, being fully informed."

I don't understand. This is about the patients, as far as I'm concerned. This is about the best interests of the patients, the autonomy and the self-determination of patients who make that advance directive, because they're very concerned that other people will change it when they become incompetent. I'm now hearing people saying that it's okay for physicians who don't know what it's like to have Alzheimer's, who have never had it themselves, who don't know what it's like to live in that patient's body with that patient's autonomy. They are making decisions for them, and I call that physicians playing God.

The Supreme Court was very clear on section 7 of the charter. I am hearing people telling me that the Supreme Court didn't know what it was talking about, that the doctors know better than patients what a patient requires, especially if they disagree with the patient's advance directive. I don't understand advance directives to be about that at all.

I'd like to hear from Monsieur Deschamps and Mr. Cohen about this. Why is it that other people believe that they have the ability to make the decision for a patient who has obviously made that decision in advance, because they were scared of being *non compos mentis*?

The Joint Chair (Hon. Yonah Martin): Go ahead, Mr. Deschamps.

[Translation]

Mr. Pierre Deschamps: Thank you, Madam Chair.

To respond to Dr. Fry, I'll repeat what I said in my remarks that Canadian laws at both federal and provincial levels are evolving toward a recognition and acceptance of advance requests for medical assistance in dying. The problem or challenge Parliament faces is to ensure that people who request assistance in dying get it at the right time, when they are in a vulnerable position. We'll definitely get there, but Parliament has to put appropriate safeguards in place to enable people to exercise that right.

What the Supreme Court said in the Carter judgment is that Canadian citizens must be treated equally but that the idea is not to deny a right to people who are vulnerable to a degree but rather for Parliament to put appropriate safeguards in place. It was—

[English]

Hon. Hedy Fry: I understand that, Monsieur Deschamps, and I'm not being rude, but I would like to hear from Dr. Cohen-Almagor.

The Joint Chair (Hon. Yonah Martin): Dr. Cohen-Almagor, you have 30 seconds.

Dr. Raphael Cohen-Almagor: I'll make two very short comments. One is that any advance directive should be restricted by time. When I assisted the legislation of the Israeli law, we set up a framework whereby people could renew the living will or advance directive every five years. That's the first comment.

Second, Dr. Fry, you have put a lot of emphasis on the autonomy of the patient, as do I. The question that we have to ask ourselves is, what happens when autonomy ceases? My answer is that if autonomy ceases, there's no euthanasia, because there's no autonomy. That's a very simple sort of a border that we have to draw.

• (1905)

The Joint Chair (Hon. Yonah Martin): Okay. Our next—

Hon. Hedy Fry: I disagree with that.

The Joint Chair (Hon. Yonah Martin): —questioner is Monsieur Thériault, for five minutes.

[Translation]

Mr. Luc Thériault (Montcalm, BQ): Thank you, Madam Chair.

To avoid interrupting a discussion with a witness, I will first introduce the following notice of motion:

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;
- (b) 12 hours for testimony related to advance requests;

(c) 12 hours for testimony related to mental health;

(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'll go to Mr. Deschamps first.

First of all, welcome, Mr. Deschamps, and thank you for being with us today.

I'm sure you'll agree with me that medical paternalism has had its day. First it was overtreatment; then they tried to provide better palliative care. Many practices are being considered, such as refusal of treatment, discontinuation of treatment and so on.

The government's role is not to be paternalistic or to decide what's good for the patient, but rather to provide patients with conditions in which they can exercise free choice, choice made by free and informed consent. I imagine you agree on that principle.

Don't you?

Mr. Pierre Deschamps: Yes, I absolutely agree on that principle.

What I'd like to tell you is that, if you, as federal legislators, decide to make it legal to use advance directives respecting medical assistance in dying, you must consider the situation of the individual who, when the time comes, will ask us to apply or not to apply those directives. Safeguards must be put in place. They may include a double or triple assessment, for example.

You also have to consider the fact that, when we talk about executing the request—

Mr. Luc Thériault: I apologize for interrupting, Mr. Deschamps. My speaking time is unfortunately limited. So I'll clarify my question so I can better direct your answer.

Let's consider safeguards, since you raised the point. I noticed you emphasized robust safeguards in your opening statement.

What do you think those measures might be?

Mr. Pierre Deschamps: Two of them come to mind.

First, currently, an assessment by two physicians is generally requested for medical assistance in dying. We should perhaps be able to request a third opinion from a physician with specialized knowledge of the person's medical condition. I'm not thinking of family physicians, although I don't doubt their competence. Sometimes in these cases you need the opinion of a physician who has specific knowledge of, for example, Alzheimer's disease.

Second, a certain assessment period should be provided for. Here's an example. Consider the case of a woman who has signed advance directives or an advance request for medical assistance in dying. Her son begins the process at some point, believing that his mother has reached the stage where action should be taken on her request. At that point, time should be taken to evaluate the case and assess once again whether it's necessary to activate that request before providing medical assistance in dying. All other existing conditions should also be protected.

Those are two measures that I think Parliament should bear in mind if it wants slightly more robust safeguards to accommodate to the person's vulnerability at that point.

• (1910)

Mr. Luc Thériault: Thank you.

[*English*]

The Joint Chair (Hon. Yonah Martin): *Merci.*

Next, we will have Mr. MacGregor for five minutes.

Mr. Alistair MacGregor (Cowichan—Malahat—Langford, NDP): Thank you, Madam Joint Chair. Senator Cowan, it's good to see you. Welcome, Ms. Long, from Dying with Dignity.

I want to give you a chance to respond to what we've heard so far in this session.

As you're very well aware, there are several dimensions to advance requests. There is the status of the patient, the clarity of communication, the strength of relationships, but there are also a lot of challenges. Intolerable suffering is a very subjective thing, and in the case of someone who is unable to communicate, it can be hard for an outsider to determine what their level of intolerable suffering is or whether it's meeting the definitions placed in their advance request. Also, there's informed consent, the role of third party decision-makers, the potential conflict between anticipated and present circumstances.

From both of your viewpoints, I want to give you a chance to respond on how we could set up a system that takes into account those very real concerns that exist out there.

Hon. James S. Cowan: Helen, do you want to go first?

Ms. Helen Long: Sure.

Yes, there are concerns and there are things we would need to do. In terms of informed consent, the individual should obviously know the disease state, the trajectory of their diagnosis and how things are going to go so that when they're describing, in their advance request, that point at which they would like MAID, it's a clear description. I think the description needs to go beyond "when my family can't recognize me". Perhaps it's a specific state or stage in a dementia diagnosis, and very detailed.

I think it's also important to note the use of language. This is an advance request; it's not an advance directive. The request is made. We believe that all of the eligibility requirements that exist for MAID, as outlined in the current legislation, should still be met—so the two assessments and all of those pieces. Then the clinician never has to go ahead with the procedure if they don't feel the indi-

vidual meets the bar that's been set. It is a request, not a directive, and I think it's important we remember that language.

Hon. James S. Cowan: It's good to see you again, Mr. MacGregor.

I only add that we go back to this being about the patient and about the individual. It's a clinical assessment by a medical professional as to competence. Medical professionals make these kinds of assessments every day in their practices. They're well versed and well trained in assessing competence, and if there is any doubt, then obviously they don't certify the compliance with the strict criteria that are set forth in legislation.

The legislation, as originally in Bill C-14 and then as modified by Bill C-7, has very strict criteria, very strict safeguards. I think there was significant improvement in Bill C-7, because some of the safeguards that we thought about or that Parliament put in place back when we began this journey turned out to be burdens or barriers rather than safeguards, so they were properly modified last year.

I think that as we learn more about the evolution of MAID in Canada, we have lots of experience here in Canada and, as I said in my remarks, there is simply no evidence of abuse, of coercion, and it is, as I said, about the individual's decision. It's not about what other people might think that decision ought to be.

Mr. Alistair MacGregor: Thank you for that.

I have just over a minute left.

Do you have any comments on how advance directives for care that currently exist under provincial jurisdiction and a possible future federally permitted advance request for medical assistance in dying would interact?

Ms. Helen Long: I don't believe they necessarily would.

I think an advance directive is direction around treatment you would like to receive in your health care. An advance request is a request for MAID to be carried out when you reach a state that you have identified and described and you meet the eligibility criteria.

I don't know that there is necessarily any connection between the two pieces.

• (1915)

Mr. Alistair MacGregor: Thank you.

That's all for me, Madam Joint Chair.

The Joint Chair (Hon. Yonah Martin): Thank you, Mr. MacGregor, and thank you to the witnesses.

We now go into the first round of questions, or the second round. It's for senators. I will turn it back to my joint chair.

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

[*Translation*]

We will begin with Senator Mégie.

Senator Mégie, you have the floor for three minutes.

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

My question is for the Honourable James Cowan and Ms. Long, if she also wishes to respond.

Do you agree with Mr. Deschamps on safeguards, or do you think the current safeguards are adequate in cases of dementia and advance requests for medical assistance in dying?

Do you have any other suggestions on this point?

[English]

Hon. James S. Cowan: In the brief that we'll be filing in the next few days, we go into our recommended safeguards in some detail. We recommend for advance requests both when there is a diagnosis and when there is no diagnosis, in this case with more strict safeguards. The main difference is that we recognize that without a diagnosis, the request ought to be time-limited. I think one of our colleagues on the panel mentioned that specifically. We would agree. We would suggest a five-year period and suggest that such a request would need to be renewed every five years in order to be considered at a later stage.

The safeguards that in place now in Bill C-14, as modified by Bill C-7, are very strict and I think are perfectly fine.

[Translation]

Hon. Marie-Françoise Mégie: Thank you.

The Joint Chair (Hon. Marc Garneau): Is that your only question, Senator Mégie? You have a little more than a minute left.

That's it? All right.

[English]

We will now go to Senator Kutcher.

Senator Kutcher, you have three minutes.

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

Before I start my three minutes, I'm asking you if you would mind asking one of the witnesses for more information. There was a statement made by Dr. Cohen-Almagor that advance requests are often made without fully informed consent. I would like you to ask him to provide the data to support that statement, please.

Senator Cowan, it's nice to see you again. Thank you for being here with us. My questions will be for you.

We have the Ipsos 2021 research that looks at advance directives and at mental illness as a sole condition, with the vast majority of Canadians supporting MAID for both of those. I wonder if the evidence of that study could be put into the evidence record, please.

We also, however, hear ideological, philosophical and theological arguments against allowing competent people to make decisions about their own body. What's your opinion on the disconnect between what a substantial majority of Canadians report and arguments that are made by other people, not the competent person who is suffering, that they and not the competent person should make the decision about MAID?

The second question is this. Many physicians are well trained to determine if a patient does or does not have the capacity to give informed consent. Indeed, the Royal College of Physicians and Sur-

geons identifies capacity assessment as a core competency for psychiatrists. I would ask the committee to enter into evidence that document, which I can provide you.

Given your legal experience, would you say that properly trained physicians can provide capacity assessments that might be required by the courts to determine if a person has the competency to give consent for MAID?

Hon. James S. Cowan: Absolutely, Senator Kutcher. Certainly in my experience as a practitioner, I often called on medical practitioners to provide opinions as to capacity. I always found them to be ready, willing and able to do that. As you say, they are trained. That is a core competency that they have. Physicians do that every day.

I think some cases, as you would know from your own experience, are more difficult to assess than others, but that's what physicians do. It is a clinical decision made by trained professionals, and shouldn't be made by lawyers or politicians. I think it's a clinical decision, and that's what ought to be done.

There obviously are individuals who hold a different view than I do about the appropriateness of MAID and whether it ought or ought not to be permitted, and again, it is a matter of individual choice. If an individual chooses to seek MAID and meets the very strict criteria that are set forth in the legislation, then the court has said and Parliament has said that they are entitled to access that service. I don't believe others ought to impose their view, however firmly held or however strongly held, or be in a position to impose that view on others.

As you have said, and as the polls that have been conducted.... I think if we haven't already, we will shortly be updating that Ipsos poll to include recent and consistent data showing that for the overwhelming majority of Canadians of all religions and no religions, who suffer from a disability or no disability, or who have mental illness or don't have mental illness, the numbers are consistently high that they favour the MAID regime that we have and indeed are anxious that the legislation be amended and expanded to allow for advance requests.

• (1920)

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

Before I go on to Senator Dalphond, Senator Kutcher made a request, and I want to make sure that I heard it correctly. It was addressed to Dr. Cohen-Almagor.

I believe you said that you would request that Dr. Cohen-Almagor provide substantiation or evidence to back the assertion that I think you said he made to the effect that MAID is sometimes undertaken without respecting the appropriate safeguards.

Perhaps you could correct me if I didn't say that correctly, but that's what I understood.

Hon. Stanley Kutcher: Thank you very much, Mr. Chair. Yes, that's the case.

What I wrote down was that “advance requests are often made without full informed consent”. Perhaps when we get the transcript, I can ensure the clarity of what I have said so I didn't get it wrong. When a witness makes a comment like that, I think we need to have the data that the opinion is based on.

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

We're not going to deviate from our plan tonight, but Dr. Cohen-Almagor, if you understood what we've just said and if you would be prepared to provide that information in writing to the committee, it would be very much appreciated.

We'll now go to Senator Dalphond.

[*Translation*]

Senator Dalphond, you now have the floor for three minutes.

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

[*English*]

My question is for Dr. Cohen-Almagor.

I understand, Doctor, that you are opposed to advance requests out of concerns about potential abusers. That said, is there a way, if we put up a system here in Canada with a lot of safeguards, including an intermittent check before the administration of MAID and including that if the patient is showing some resistance, we won't proceed, that these safeguards will address some of your concerns or maybe all of your concerns?

Dr. Raphael Cohen-Almagor: I want to clarify that I'm not opposed to advance directives for competent, autonomous patients; I'm opposed to advance directives when it comes to incompetent patients. As I said, I sat on the committee that legislated the Dying Patient Law—

Hon. Pierre Dalphond: Doctor, I'm sorry to interrupt.

If you say that you're not opposed to advance requests when you're competent, what is the difference between asking for MAID at one point and asking for it in advance? You're talking about the same thing.

Dr. Raphael Cohen-Almagor: I refer in my testimony to the issue of dementia particularly, because I know that it's an issue in Canada.

Just imagine the following. A person has been diagnosed with dementia. It's the starting of a process that can last years. At the start, he says that he would like to die in the later stages of dementia. Now the patient says he doesn't want to die.

Then we can discern a second stage, in which the dementia is advancing. Now five years have passed, and he again feels the advance directives. If you ask him if he wants to die now and he says no, he doesn't want to die now, but would like to die at a later stage, then there's no euthanasia for that patient. At the next phase, it's going to be too late, because then the patient is incompetent. Either you are going to kill the patient—

• (1925)

Hon. Pierre Dalphond: That's not my question.

If the patient has dementia, he cannot ask for advance requests. It's too late. He cannot consent to it. However, if he was competent, why are you opposed that later on, when he reaches the stage he had indicated when he was competent, we follow the instructions?

Dr. Raphael Cohen-Almagor: It's because maybe at that time he doesn't want to die anymore, and it happens quite a lot. Orders don't—

Hon. Pierre Dalphond: So you'll go judge in that situation?

Dr. Raphael Cohen-Almagor: You want to enforce the autonomy of the previous stage of the person, when the person actually changed. What I want to say is that we always change all the time. When we are competent, we change, let alone when we don't know or understand the brain enough to make a decision about the patient now when he is in advanced dementia.

I say all the time that at any stage, the issue of advance directives for dementia patients is morally problematic; therefore, this is where I draw the line. I've nothing against advance directives when it comes to competent, autonomous patients.

The Joint Chair (Hon. Marc Garneau): Thank you, Doctor. We'll now go to Senator Wallin.

Go ahead, Senator Wallin.

Hon. Pamela Wallin: Thank you very much.

I will address my questions to Senator Cowan and Ms. Long.

As you know, Senator Cowan, the Senate dealt with this issue and proposed an amendment, which was accepted overwhelmingly by the Senate, to deal with the very conundrum that you have to make an advance request if you know your disease or illness will render you incompetent. That is the whole core of the discussion around advance request for individuals with dementia.

How do we wrestle this? We have seen in the news in the last few days endless discussions around choice and a person's right to choose what will happen to their body. How can we ensure that, if we do not allow for advance requests? It's the only way we can ensure that that patient continues to have some say.

Hon. James S. Cowan: I absolutely agree, Senator Wallin. I think that's very reason we have it.

To add to the point that was made a little while ago about people changing their minds, when you passed Bill C-7 last year, there was a specific provision inserted in there. It was a form of advance request, with “Audrey's Amendment”. It specifically provided that if the individual showed any conscious indication of resistance or refusal, then MAID would not be administered. We would suggest that it's logical to have that safeguard in place if we proceed to adopt a more expansive role for advance requests. I agree.

Hon. Pamela Wallin: Ms. Long, on the question of advance directives and advance requests, we do allow that anybody who goes in for surgery can sign a DNR, a “do not resuscitate”, and specify the circumstances. It seems to me that we're just trying to extend that very right that we give to a patient. They don't know what their state will be when they emerge from a risky surgery, so that is why they have signed the DNR.

Is this advance request not the ability to do the very same thing? We could sign it five years in advance and three years in advance and one year in advance. If you've indicated over your lifetime that you want to make those choices, would that not be a reasonable approach?

Ms. Helen Long: I think it's a very similar approach. The difference is that in the end there's an assessment process for the MAID process and an eligibility requirement that is assessed by a clinician. I agree that certainly you could make it years in advance. It could be renewed upon occasion. It needs to reflect your values and beliefs and things that are not, I don't think, as relevant in the case of an advance directive.

I think there are certainly ways to get to safeguards. We heard from the assessors and providers who have been speaking that the work that's going into building a national curriculum for MAID assessors and providers will support the ability to put appropriate safeguards in place and adhere to them.

• (1930)

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

We'll now go to Senator Martin.

The Joint Chair (Hon. Yonah Martin): Thank you, Mr. Co-Chair, and thank you to all of our witnesses.

I have limited time, so my question will be to Dr. Cohen-Almagor.

There's a pretty surprising stat from Health Canada's 2020 report on MAID that notes that 35.9% of the individuals who received MAID listed being a "burden on family, friends or caregivers" when asked about the nature of their suffering.

If advance requests were permitted, do you expect that the percentage of people who are having MAID who are worried about being a burden would increase? Is that something that should concern us? Would you comment on that, please?

Dr. Raphael Cohen-Almagor: Oregon was the first state in the United States to legislate end-of-life physician-assisted suicide. If you look at the Oregon reports, you see that one of the repeated drives for requests is the fear of becoming a burden on the family. People don't like it, and therefore they'd rather die. I think it's very unfortunate that this is the cause for death. That's my call for compassionate care, for palliative care and for helping people to not believe and feel that they are a burden on the family.

I'm not sure what the legislation is going to bring about, but I think all of us in this virtual room want to have an autonomous patient who is able to dictate the trajectory of life. When it is influenced by becoming a burden on the family, then of course autonomy is gone. We would like to retain the autonomy of the patient. That's my concern. That's why I'm here. I want to have a say for autonomy. I want all other factors to be at least addressed in a good and responsible fashion.

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

I think we've come to the end of this hour, Mr. Garneau.

If I may, I will take this opportunity to thank all of our witnesses for their testimony. Some follow-up was mentioned during the questioning, particularly from Senator Kutcher. That is something we will follow up on.

We'll take a moment now to prepare for the second panel. Thank you so much.

Dr. Cohen-Almagor, I know it's very late for you. Thank you so much.

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

We'll suspend at this moment.

• (1930)

(Pause)

• (1935)

The Joint Chair (Hon. Marc Garneau): Welcome to the second panel this evening.

We have the pleasure of having with us Dr. Melissa Andrew, professor of medicine in geriatrics at Dalhousie University and with the Nova Scotia Health Authority, as well as Mr. Michael Bach, managing director, Institute for Research and Development on Inclusion and Society.

[Translation]

We also have Dr. Georges L'Espérance, neurosurgeon and president of the Quebec Association for the Right to Die with Dignity, or AQDMD.

Welcome to you all.

[English]

We will begin with opening statements from each of you in the order in which I named you. You will have five minutes. That will be followed by a question period.

Please wait until I give you the sign to speak. Speak slowly and clearly. Try to stay within the time limits. You may speak in the official language of your choice, English or French; we have that translation capability.

If there is a problem, let me know. We'll interrupt proceedings until we can sort that out.

With that, I would like to invite Dr. Melissa Andrew to start us off with a five-minute opening statement.

Dr. Melissa Andrew (Professor of Medicine in Geriatrics, Dalhousie University, Nova Scotia Health Authority, As an Individual): Thank you very much.

I practise internal medicine and geriatrics, and most of my work is with older adults or people dealing with geriatric syndromes such as frailty and dementia. I often care for patients who are making important and potentially life-limiting decisions and regularly assess patients' capacity for decision-making in these contexts.

Thinking about our discussion today, it's useful to reflect on why people might seek MAID and why they would wish to use an advance request. People seek MAID because they have symptoms that, to them, cause or are anticipated to cause intolerable suffering as these symptoms progress. For most conditions, this does not inherently lead to loss of decision-making capacity except in defined situations, such as progression of brain tumours and delirium at end of life.

In the case of dementia, the loss of decision-making capacity is often inherent to the very symptoms a person might consider to be intolerable suffering. We could thus see a lack of provision for advance requests as something that impacts this vulnerable population in a somewhat discriminatory way because of the very symptoms of their condition. We should also recall that people living with dementia can currently be eligible for MAID, but it's just at a time that would be much earlier than they might otherwise choose if they had the comfort of knowing that an advance request could be valid.

What analogies are useful to how we can currently approach health care decision-making?

Of course, we currently do allow, and in fact encourage, people to make advanced directives to deal with life-and-death situations, including with reference to tricky conditions. We ask them and/or their substitute decision-makers to consider whether they would want resuscitation. We allow people to decline or withdraw treatments at any time in their illness journey from pre-diagnosis to late stage. These are sometimes called "hastening decisions" because they may hasten death, but in all these cases, clinicians enter into discussions with the patient and/or decision-makers to ensure that they're making an informed choice and that they meet the generally accepted threshold for capacity in these decisions. Assuming these criteria are met, the person's wishes regarding these decisions are respected.

Regarding the question of whether there is an ethical and legal difference between withholding and withdrawing care, which was mentioned earlier, this is, of course, debated by many ethicists and others. *Carter v. Canada* concluded that MAID was not different from other end-of-life decisions, so it behooves us to think about that in relation to this question about advance requests for MAID.

What are some concerns and counter-arguments about advance requests?

One counter-argument is that it would be too difficult to operationalize the exact definition of what the person has deemed to be "intolerable suffering". There, of course, may be some grey areas. Indeed, our clinical work is often all about the grey areas. As an example, I've cared for patients whose degree of suffering was extremely clear to all involved; these people lived with complete torment that was not possible to relieve, despite intensive management attempts. It has been heartbreaking to hear from some families that the person's wishes were very clear: They would not want to live in such a state and had wanted to request MAID in advance, but were not able to.

Counter-arguments also bring up grey areas in interpretation. Is this the state the person meant? How do we word the advance re-

quest in way that allows for optimal clarity? For example, how would we operationalize a statement like, "Once I no longer remember my family, I want MAID"? What if their cognition fluctuates? Did they mean every family member, or just their closest ones? Is it about forgetting names or is it a complete lack of recognition? There are safeguards to address some of these concerns that have been proposed, such as templates and detailed wording, including consultations with appropriate stakeholders and possibly adjudication panels.

Clinicians may also worry about performing MAID if the pre-stated condition appears to be met, yet the person seems content in their current life. Again, even in those cases, safeguards could be implemented, as has been discussed earlier. People whom I've heard from who are living with dementia more often worry about distress and agitation rather than about simply memory loss when it gets right down to what really defines their suffering.

Another concern is of course the "current self versus future self" argument, which we heard earlier as well. Many cite evidence that people adapt well after conditions like spinal injuries once they have the lived experience. However, on the flip side, we risk not valuing the current and often long and strongly held values and beliefs that a person now has if we're telling them that their future wishes may change. Here stigma becomes the very relevant consideration. This may contribute to feelings of further marginalization and people living with an already stigmatizing condition.

Some worry that advance requests for MAID may be made with too much consideration of financial costs and one's burden on others. This of course leads to discussions about how we provide social supports and care for people living with progressive conditions that may impair their future decision-making and how we value their quality of life. The recent discussions of how we provide long-term care, which has been stressed beyond the breaking point by COVID, brings this issue to light. Clearly this is something that requires a systems fix, as well as careful ruling out of coercive factors if and when advance requests are considered.

In the bigger picture, it's also hard to extract this issue from the overall systems of dementia care that we have in Canada, which are suboptimal. We provide expensive care, but not necessarily good care, and we have underfunded dementia research. We treat people living with dementia in ways that do not further their overall well-being, such as lengthy stays in emergency rooms and in hospitals for behavioural expressions of dementia, which is pretty much exactly the wrong environment to help these people.

The Joint Chair (Hon. Marc Garneau): Doctor, could I ask you to wrap it up, please?

Dr. Melissa Andrew: Yes.

This provides an opportunity to advocate action on the national dementia strategy. Just as we talk about the need for strengthening mental health care in the context of MAID for mental disorders and we worry about people seeking MAID for physical conditions when palliative symptom management is suboptimal, and we appropriately see this as a time to call for strengthening those services, we must also see that this issue of advance requests for MAID is intimately tied with the quality of dementia care in Canada.

Thanks.

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

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

Mr. Michael Bach (Managing Director, Institute for Research and Development on Inclusion and Society, As an Individual): Thank you, joint chairs and honourable members of this committee, for the opportunity to participate in these hearings.

I urge the committee not to recommend adoption of advance requests for MAID for three main reasons.

First, advance requests as a planning tool cannot deliver meaningful consent. What would it look like if advance requests for MAID were adopted into the Criminal Code's regime for legal exceptions to its prohibition on assisted suicide, knowing what the Alzheimer Society of Canada has called the "rising tide" of dementia in this country? In the decades to come, more and more people who don't know what is happening to them are caused to die. Most of them are women with cognitive disabilities.

Advance care planning, in which advance requests for MAID would be added as another tool, has been shown in a series of systematic studies and reviews to be ineffective. People are simply unable to reasonably predict future preferences, capacities or circumstances, which will impinge directly on future decisions about their health care. If that predictability is impossible, it leaves it entirely up to substitute decision-makers to determine that a person is suffering sufficiently to intentionally cause their death.

Remember that advance care plans do not represent consent to anything; they express assumptions and wishes about future states to guide prospective substitute decision-makers. In this scenario, it is the consent of substitute decision-makers that determines if and when a person dies.

In no way would such a practice meet the Supreme Court of Canada's requirements in Carter that assisted suicide is justified only in cases of "a competent adult person who...clearly consents to the termination of life." Valid consent was pivotal in Carter.

Second, it's most likely that stigma is driving Canadians to call for advance requests, rather than a defensible claim for autonomy. Although much has been said about the Ipsos polls conducted for Dying with Dignity Canada and the 2021 poll reports that 83% of Canadians support access to MAID through advance requests, it's important to also consider the 2017 Leger poll conducted for the Alzheimer Society of Canada. It shows that the majority of Canadians believe that people living with dementia are likely to experience discrimination and that they are ignored, dismissed, taken ad-

vantage of, feared or met with distrust, etc. A majority of Canadians who live with dementia confirm this experience.

Given the stigma and fear about dementia that weighs on Canadians' consciousness and directs their actions and inactions, is it any wonder that a majority might advocate in favour of advance requests to cause the death of the cognitive strangers that we project in our midst and into our own futures? Is this a reasonable basis for law reform? Is theirs a defensible claim for autonomy rights? Should we submit to the Ipsos poll when the Leger poll tells us such a disturbing story about our collective consciousness and the current realities of growing old in Canada? Surely our law reform and public policy efforts should shift to fast-tracking strategies for dementia-inclusive communities and eliminating stigma, as the 2019 national dementia strategy calls for.

Third, it would open the door to MAID for people who are unable to consent but who don't have advance requests. What argument would there be to a substitute decision-maker who goes to court to request access to MAID for their family member with a significant intellectual disability, a traumatic brain injury, dementia or Alzheimer's, because they are suffering intolerably in the circumstances but are unable to consent and don't have an advance request? Opening the door to advance requests will inevitably lead to litigation charging that when it comes to providing MAID to people who are not competent but are suffering, it's discriminatory to restrict it only to those who have advance requests, which don't constitute informed consent in the first place.

The Supreme Court reasoned in Carter that what they acknowledged as a "slippery slope"—their term—in other countries would not happen in Canada. They said explicitly that euthanasia for minors or people with psychiatric disorders would not happen here because our "medico-legal culture"—their term—is so different from Belgium's, for example. Obviously, they were wrong. Authorize advance requests and the hinges start to come off the door.

We should remember that the justices deciding Carter stipulated that their reasoning applied to the case before them. They didn't even mention advance requests. I suspect that is because any such measure represents a profound violation of the principle of informed consent, which they so clearly established as a fundamental safeguard.

Thank you.

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

We'll now go to our third witness.

[Translation]

Dr. L'Espérance, you have the floor for five minutes.

Dr. Georges L'Espérance (President and Neurosurgeon, Quebec Association for the Right to Die with Dignity): Thank you, Madam Chair and Mr. Chair.

Senators and members of Parliament, the Quebec Association for the Right to Die with Dignity thanks you for holding this meeting.

I am a neurosurgeon retired from surgical practice and now an active provider of medical assistance in dying. Our suggestions here are intended as principles that should guide all thinking on such matters as personal self-determination, respect for expressed wishes and values and dignity in life and death without medical paternalism or religious or ideological dogmatism.

Our brief has been forwarded to you and contains numerous hyperlinks.

Today I will outline our thoughts on advance requests for medical assistance in dying and say a word about two other equally important topics.

All capable persons who have received a diagnosis of cognitive neurodegenerative disease should, while all their faculties are intact, be able to indicate by an advance request that they wish to obtain medical assistance in dying at such time as they deem appropriate for them, based on their values, regardless of their cognitive state at that time. That position is supported by nearly 80% of Quebecers, according to a scientific survey conducted by the Collège des médecins du Québec in fall 2021.

In February 2016, during consideration of Bill C-14 within these walls, that's also precisely what was clearly spelled out in recommendation 7 of the report prepared by the Special Joint Committee on Medical Assistance in Dying, consisting of senators and members of Parliament.

In Quebec, a transpartisan special committee of the National Assembly tabled an informative report on this subject, which you have no doubt seen, on December 8, 2021.

As a neurosurgeon, and like many clinical experts, I want to point out here that what some call a “happy dementia” is an oxymoron used to describe the condition of a human being who is no longer what he was during his life. Claiming that such an individual may have changed his mind about seeking medical assistance in dying because he seems cheery and fine, whereas, by definition, he is no longer the same person, may seem like an insult to that person's intelligence and, especially, to the person himself, like a negation of the personality he had initially and throughout his life.

I also want to state that medical assistance in dying does not compete with palliative care in any way but is an additional compassionate tool in end-of-life care. Medical assistance in dying takes absolutely nothing away from palliative care, financially or otherwise, and requires the presence of a physician or nurse for only a few hours in total, at no cost to the system.

An absence of physical suffering can in no way preclude future existential suffering that the person may express while still capable of doing so. It is important to note that eligibility for medical assistance in dying brings serenity and peace of mind and enables those afflicted to live fully in the present without experiencing anxious

thoughts of a long road of suffering and loss of dignity as a result of a disease that leads inevitably to a slow death.

Those of you who may have experienced the pain of seeing a loved one disappear into the abyss of dementia will definitely not want to experience the same long existence without living that is the reality of dementia.

Our recommendation is that medical assistance in dying by advance request be authorized upon confirmation of a diagnosis of cognitive degenerative disease and at the time the person has decided in advance by designating a representative.

Mental health disorders taken together are a real disease that causes undeniable suffering. Continuing to rule out mental health issues can only lead to legal challenges, a process that is complex and unacceptable for the patient concerned. Our recommendation is that medical assistance in dying be accessible by March 2023 for persons with mental health problems based on strict clinical eligibility criteria to be established with experts in the mental health field.

We also recommend that persons with significant cognitive impairment be completely and permanently disqualified from receiving medical assistance in dying, except where there is absolute certainty that the person's decision-making ability is intact.

Lastly, it is the association's view that medical assistance in dying must be extended immediately to mature minors 14 to 18 years of age. We recommend that medical assistance in dying be accessible to mature minors suffering from an incurable physical pathology, but not to those suffering from mental health pathologies.

Thank you.

I will answer your questions as best I can, based on my knowledge.

The Joint Chair (Hon. Marc Garneau): Thank you for your testimony, Dr. L'Espérance.

I now give the floor to my co-chair, Senator Martin.

[*English*]

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

We will begin with questions from the House, and each questioner will have five minutes.

Let's begin with Madame Vien for five minutes.

[*Translation*]

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

Thanks to the witnesses for being with us this evening. The subject before us is very important, very moving and complex.

I am a former Quebec government minister. In 2014, I was in that position and voted for medical assistance in dying. Today, Quebec members have issued a news release to urge the present government to proceed with the changes proposed by the medical assistance in dying committee in Quebec based on a broad consultation.

The studies we are currently conducting on the subject are very interesting. We have to take the time to consider the right issues. We have to avoid moving ahead blindly and instead be clear about what we're doing. It's obvious that the positions expressed here this evening are entrenched.

Dr. L'Espérance, earlier the Honourable James Cowan and Ms. Long, from Dying with Dignity Canada, said that people should go ahead with or without a diagnosis. What you're telling us this evening is that you have to establish a diagnosis.

Dr. Georges L'Espérance: Yes, a diagnosis has to be established. Otherwise anyone 20 years old or more could request medical assistance in dying regardless of what has happened in their lives, such as a head injury or stroke. These aspects are already covered in large part by the advance directives, if the person has made them known. Medical assistance in dying can't be requested through advance directives.

What we're requesting is that a patient who has received a diagnosis of cognitive neurodegenerative disease be able to give advance directives specifically concerning medical assistance in dying.

All my colleagues agree that a precise diagnosis has to be given, whether it be of Alzheimer's disease, Parkinson's disease or Lewy body dementia, for example.

Mrs. Dominique Vien: In this study we are also going to discuss mature minors. Mental health is also, of course, going to be included in our deliberations, although we won't be able to address these questions this evening, because we would run out of time. In any event, what we'll be looking at today are advance requests for medical assistance in dying.

What are the most important precautionary measures we should be thinking about?

Dr. Georges L'Espérance: For advanced directives, you might find me somewhat chauvinistic, but Quebec's proposals seem very reasonable to me. What's involved is designating a trusted relative, friend or substitute, to be responsible for alerting the care team of the patient's condition when it has reached the stage specified by the patient as when they wanted to receive medical assistance in dying. After that, the assessment would be carried out by the care team.

It's important never to forget that these patients are not being treated only by a doctor. They always have a care team consisting of a nurse, a social worker, etc. I can't see anything wrong with a wait time of three, four or five months to assess requests. There is nothing urgent when the family member says that his father or mother has reached the stage at which they had said they wanted to receive medical assistance in dying. The safeguard would be to plan for a period of time before doing an assessment.

The other problem is decision-making capacity. For a patient with a cognitive neurodegenerative disease, this capacity disappears all at once. They might reaffirm their desire for medical assistance in dying. It would be relatively easy to assess the patient's decision-making capacity every year or every two years, for example. As soon as the patient is deemed to be incapacitated, a formal assessment would be carried out by two doctors.

Mrs. Dominique Vien: Earlier, a witness also told us that the request would have to be reiterated at a specified frequency.

Dr. Georges L'Espérance: The problem is setting this frequency. If it has been agreed that the request is to be reiterated every three years, and after the first three years, the person is already incapacitated, it's a problem.

Mrs. Dominique Vien: Yes, I understand.

Dr. Georges L'Espérance: That's why one of the safeguards could be an assessment of patient decision-making capacity when they are asked to review their position.

Mrs. Dominique Vien: I'll be brief, because time is running out.

My understanding is that you are a medical assistance in dying provider.

Is that correct?

Dr. Georges L'Espérance: Yes indeed.

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

Mrs. Dominique Vien: Thank you.

It's clear that there are people who are worried. In the course of your career, Dr. L'Espérance, have you ever seen or heard about any missteps?

Dr. Georges L'Espérance: No, absolutely not. At least none of the figures I'm aware of have demonstrated that there have been any in Quebec. When there are somewhat more sensitive issues, we in Quebec have established a private forum of doctors, one that is closed and confidential. The same thing happens in the rest of Canada, which has the Canadian Association of MAID Assessors and Providers, CAMAP. When there are difficult cases, doctors discuss them among themselves.

Mrs. Dominique Vien: Thank you.

We really don't have much time left. Would it be possible to send us the surveys you were just talking about?

I'd also like to point out that I don't have access to your brief. I believe that's because it has not yet been translated. We will therefore familiarize ourselves with it afterwards, Dr. L'Espérance.

Thank you very much, Madam Chair.

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

[English]

Next we'll have Monsieur Arseneault, for five minutes.

[Translation]

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

I'd like to thank all the witnesses.

Dr. L'Espérance, I'm going to ask you a series of questions along the same lines as those from my colleague Ms. Vien.

I find it interesting. It's as if you were taking a middle-ground position on the matter of advance requests. There are people who are squarely in favour and others who are clearly against. You are in favour, but only once the diagnosis has been received.

Dr. Georges L'Espérance: Yes, absolutely.

Mr. René Arseneault: You gave examples of neurodegenerative diseases and spoke about strokes. There can be cases where, even among young people, the first time something like that happens, it's over. In other words, those affected will never be in a position to say they want to make an advance request, and the situation can only get worse.

How would you view a situation like that?

Dr. Georges L'Espérance: I may have expressed myself poorly, and if so I'm sorry.

Cognitive neurodegenerative diseases like Alzheimer's fall into a class of diseases. It excludes people who are brain-damaged, whether as a result of cranial trauma, strokes, or brain hemorrhages. That's an entirely different category. These patients will either have already given their advanced directives, which is nevertheless relatively rare, or not done so. If they have not, then the decision burden falls to the care team and the family, as is currently the case with respect to aggressive therapy.

Cognitive neurodegenerative diseases are an entirely different category.

Mr. René Arseneault: Good. You've expressed that very well. Thank you for reminding me of what exactly you had said before. It's come back to me now. That's exactly what you had said.

Now, let's talk about an instance in which someone might receive a diagnosis for a neurodegenerative disease like Parkinson's. You mentioned a few of these diseases. Alzheimer's is the one we hear about the most. I come from a remote rural region, where it's difficult to have access to specialists. We often have to go far and wide to find a specialist, and it can be tough. Theoretically, can someone, at the time of receiving a diagnosis, already be at an advanced stage of the disease and incapable, from the specialist's standpoint, of objectively deciding on their own to make an advance request? Do you believe that's possible?

Dr. Georges L'Espérance: I don't have numbers for you, but based on 35 to 40 years of my own experience, I think it would be very difficult. When people begin to have memory, judgment or other problems, they consult someone. Most of the time, it's their GP who broadly diagnoses neurodegenerative diseases. For a more accurate diagnosis, it often requires a specialist like a neurologist, a geriatrician or a psychogeriatrician.

Mr. René Arseneault: Thank you, Dr. L'Espérance. I don't have much time left either, and would like to ask Dr. Bach a question.

Dr. Bach, you appear to be saying that disabled people don't suffer because of their serious and irremediable condition, but rather from a lack of support and services for their disabilities.

I was on the first joint committee on medical assistance in dying, and clearly remember when Mr. Fletcher, a quadriplegic and former minister in the Harper Cabinet, came to tell us that he did not have suicidal ideation, that he was well cared for and treated, but that if

one day he were to decide to request medical assistance in dying, he wouldn't want to be lectured to by anyone.

We've heard your comments. What would you say to Mr. Fletcher?

[*English*]

Mr. Michael Bach: I certainly accept that people live with grievous and irremediable conditions that cause them immense suffering. Some of that is motivated by lack of supports, but I know that in many situations that's not the case.

I guess my point this evening is that it's very problematic to move to introduce these authorizations for advance requests, because advance requests are not consent, remember. Someone who is going to be authorizing the death of someone else is a substitute decision-maker. That's the problem here.

When you make an advance request, as the special commission report in Quebec tabled in the National Assembly in December said, yes, advance requests should be made in a free and informed manner, but that's not about consent to something that's going to happen in five years. I think we just have to have our eyes wide open to the reality that we're going to have substitute decision-makers causing the death of another person who has no idea of what's going on. They are not consenting to their death.

You can't consent to the death years in advance, because you don't know the circumstances. Informed consent is all about understanding the circumstances in the current moment. We're crossing the Rubicon—

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

We'll go next to Luc Thériault for five minutes.

[*Translation*]

Mr. Luc Thériault: Thank you, Madam Chair.

My question is for Dr. L'Espérance.

Dr. Cohen-Almagor, who was in the previous group of witnesses, said—I'm speaking to the neurologist—that we don't know, or understand enough, about the brain to think that we can intervene by means of advance requests.

What do you think of that? What state is the brain in when we reach the final phase?

Dr. Georges L'Espérance: To begin with, you are attributing something to me that I am not. I'm a neurosurgeon, not a neurologist.

We can tell that the brain is functioning properly when patients have all their capacities. We have mechanisms to check on a patient's capacities. That, moreover, is what we do every day, whether by operating on patients, or responding to their requests for medical assistance in dying. The first thing we do is a capacity assessment.

Now, when patients have dementia and have lost their capacities, I believe everyone accepts the situation. What is the state of their brain? Well, the brain is not functioning as well as it used to. I can't tell you much more than that.

How can we say on the one hand that a patient is functioning less well, has lost capacity, and at the same time, that we no longer know whether that patient made the right decision? And yet, throughout life, the patient reported wanting to live in such and such a way and not wanting to reach the end of life in such and such a condition. It's this aspect of the discussion and the argument that I have trouble accepting, from my own standpoint.

Mr. Luc Thériault: Some witnesses told us that a person with a degenerative disease is no longer the same person. There are different stages to the disease. So people who have made an advance request are stating what they want and it's assumed that it is a solemn moment between them and their doctor.

How would you respond to the argument that it's no longer the same person when the time comes to follow through on the advance request?

Dr. Georges L'Espérance: Well, they are no longer the same person they were throughout their life, whether at 60 years, 70 years, or 80 years. Why, all of a sudden, with dementia, are they no longer the same person? It's true that it's no longer the same person because they no longer have the brain they used to have when they lived and related with other people.

We also regularly make decisions through other people for those with brain damage, who have suffered cranial trauma, massive strokes, and so on. We make decisions for them, because they are no longer there to tell us what they want or don't want. We make decisions for them because they have left advance directives with respect to aggressive therapy.

In medicine, it's a fairly regular occurrence for us to make a decision for the patient with the family, friends, etc. We generally do so for cases of aggressive therapy, but then we are no longer dealing with the same person.

Mr. Luc Thériault: I was questioning Mr. Deschamps earlier. He said that heroic treatment was called for. He mentioned a third doctor to confirm the advance request.

Isn't there a danger of adding so many conditions and obstacles that in terms of your practice in the field, moving ahead would be virtually impossible in the end?

Dr. Georges L'Espérance: Yes, you're right. The answer is in your question.

What we have learned in Canada over a period of six years now, and slightly longer in Quebec, is that we never encountered the slippery slope against which everyone was warning us. A doctor assesses a patient and a second doctor or a clinical nurse does an assessment to determine whether the patient's circumstances meet the criteria. To my knowledge, and according to what is reported to us by Quebec's commission on end-of-life care and coroners elsewhere in Canada, there have been no problems of this kind.

In Quebec, there are confidential discussion groups made up of doctors. In Canada, there is the CAMAP, where disputed cases are

discussed. Some prefer not to go in that direction. There is discussion, but it is about a clinical plan.

I will conclude by saying that decisions like these are made every day in neurosurgery and cardiac surgery. The administration of all these aggressive treatments—and I am using the word correctly—of our patients is a decision made in accordance with our collegial procedure.

Mr. Luc Thériault: Thank you very much.

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

[*English*]

Mr. MacGregor, you are next. You have five minutes.

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

Dr. Andrew, I'd like to start with you. In your opening remarks, you were going over the advance directives of care that are currently allowed in our provincial medical system. Before patients go through a major surgery, for example, they could talk about a "do not resuscitate" order. There also could be different examples of withdrawal of care.

Could you tell us what some of the more common forms of withdrawal of care would be? Would it be if a machine was breathing for them? Perhaps you can just elaborate on that.

Dr. Melissa Andrew: Sure. Thank you for the question.

Really, you can think about these decisions as happening at every stage along somebody's entire journey. Even people who have no symptoms at all may decide that they can justify, for good reasons, that they do not want to have testing, screening, examinations or X-rays. They don't want to know what they would find, or they don't want treatments or don't want to go down that road. They could decide that before they even have any symptoms. They might decide it when they have such symptoms as a chronic cough or loss of weight. They might consider their options and decide not to have the investigations because they don't want to go down that road, even if it would potentially identify a cancer or something that potentially could be treated, with some lengthening of life.

Somebody who's diagnosed with a probable serious condition, such as a mass identified at the first stage of imaging or testing, may decide that they don't want to have further investigations, like a biopsy, to find out what it is. Again, they do not want the treatments that would put their quality of life in jeopardy once they weighed the options. Someone who has a diagnosis of a serious condition may decide that they don't want any recommended treatments once they have the options in front of them. Surgery, chemotherapy, radiation—these all come with very significant impacts on people's quality of life and well-being. People who have kidney failure, for example, may decide that they don't want dialysis—

Mr. Alistair MacGregor: Dr. Andrew, I'm sorry for interrupting. I just want to give you a specific example.

Let's say a patient's about to go through a major surgery. Something happens—a major blood clot hits them—and they are left with a debilitating stroke. They're completely unresponsive. They're basically brain-dead. They have given advance directives of care specifying withdrawal of care.

Let's say I'm in this condition. I don't want you to feed me anymore. I want you to unplug the machines. Are those specific examples?

Dr. Melissa Andrew: Yes, they are, certainly.

Mr. Alistair MacGregor: In that case, you have these advance directives of care and a patient has suffered a massive, debilitating stroke. How, then, does our law allow for them...? We're talking about consent. How is consent understood in that case, when a patient is unresponsive and brain-dead, but you have to listen to the directives they gave you earlier? We're talking about consent. They're obviously not able to give you consent, but you are withdrawing the care that is keeping them alive.

Dr. Melissa Andrew: Part of the reason we do that is that we want it to be based on what they would want. That's why we listen to an advance directive preferentially to just deciding what's in their best interest. Of course, the ideal advance directive might include naming a substitute decision-maker who can help walk through the different options that are presented in front of them—somebody who's trusted and chosen by the person.

Mr. Alistair MacGregor: Absolutely.

Yes, we do have real-world examples right now of people who aren't able to give current consent but who have very specific instructions that allow people to make decisions that will ultimately result in their death through withdrawal of care, because that is what they specified.

As my final question, from a physician's point of view, what are the specifics you would like to see in a statement accompanying a possible advance request if we, as the Parliament of Canada, are going to allow this? Perhaps in the last 30 seconds you could talk about some of the specifics that physicians would really like to see. You talked a lot about clarity in how we want to see that.

Dr. Melissa Andrew: I think the detail would be really important.

Again, my examples were not just not recognizing the family. I want to understand really where that request is coming from, what you mean by that, and give people enough education around creating these advance requests that they understand what elements of the symptoms of their condition would be the troublesome ones to them.

Maybe it isn't that they forgot what they had for breakfast but that they are completely traumatized anytime someone comes near them to help them with their incontinence product, or something like that. The suffering can be quite severe.

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

I'll turn this back to our co-chair as we go into questions for the senators.

[Translation]

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

We are now moving on to the round of questions for senators. We'll begin with Senator Mégie.

Go ahead, Senator Mégie. You have the floor.

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

Before asking my question, I'd like to suggest that the report of the Select Committee on the Evolution of the Act respecting end-of-life care, tabled on December 8, 2021, and the other document from the Collège des médecins du Québec, entitled “Recommandation de positionnement du groupe de réflexion sur l'aide médicale à mourir et les soins de fin de vie”, tabled on December 10, 2021, be tabled to the committee for the purposes of its study.

Thank you.

My question is for Dr. Andrew.

Dr. Andrew, you work with and assist people suffering from dementia. You know that when there is discussion about broadening medical assistance for dying, people fear that they are on a slippery slope.

For this clientele, what kinds of slipups come to mind in connection with advance requests?

[English]

Dr. Melissa Andrew: Sorry; I was relying on my French. I'm mostly following.

You said *les dérives*. What do you mean by that?

[Translation]

Hon. Marie-Françoise Mégie: It's what's called being on a slippery slope.

[English]

A voice: A slippery slope.

[Translation]

Hon. Marie-Françoise Mégie: What kinds of slipups have you seen?

[English]

Dr. Melissa Andrew: In most of my discussions with people living with dementia, they're expressing indignation, essentially, that they are not taken seriously with regard to their own wishes, because perhaps a future self is valued more than their current self.

Of course, there could be slippery-slope arguments, such that if somebody makes a request, it could be taken too far, or that somebody who's thought to be a trusted decision-maker perhaps makes a decision that is in their own self-interest as opposed to the person's interest, or perhaps they are constrained, despite what we hope, by economic or social circumstances. We know that a lot of people, particularly in their senior years, and especially those who have chronic medical conditions, have difficulties in terms of socio-economics and living situations and housing and whatnot. One can imagine, I suppose, different ways things could be taken too far in this slippery-slope type of argument.

However, maybe I'll bring it back. The other slippery slope is the uphill slope, when we don't allow people in their current state to exercise what they wish.

[Translation]

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

Do you have another question, Senator Mégie?

Hon. Marie-Françoise Mégie: No. Thank you, Mr. Chair.

We can give the rest of my speaking time to Senator Kutcher.

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

[English]

Senator Kutcher, you have three minutes.

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

Before I ask my questions, I wonder, Mr. Chair, if you could request some information from Mr. Bach: a written note to this committee providing the data that documented the evidence to support the statement he made that stigma is driving advance requests instead of the need for autonomy. That has to be an evidence-based statement.

My question, to start with Dr. Andrew, is that I would expect that an individual who makes an advance request must be competent at the time they made that request: Is that correct?

Dr. Melissa Andrew: Yes.

Hon. Stanley Kutcher: Are you properly trained to make a capacity assessment of a person's ability to provide informed consent about acceptance of treatment and withdrawal of treatment?

Dr. Melissa Andrew: Yes.

Hon. Stanley Kutcher: Therefore, you are capable and competent enough to make a capacity assessment on someone who makes a request for MAID.

Dr. Melissa Andrew: Yes, I think so, not having done it yet. I do think so, because it would be based on the same principles of the person understanding the facts, applying those facts to their situation, reasoning pros and cons, manipulating that information and then considering alternatives and being able to communicate that choice, and making sure that it's being done without coercion.

I think it would be eminently possible to do, but I also think that if it were implemented, it would be important, as part of this, to include education for clinicians and for physicians and nurse practi-

tioners who would be in these roles to ensure that they have the training to adapt their existing expertise on capacity assessments to an advance request.

Hon. Stanley Kutcher: The Royal College and the College of Family Physicians are now in the process of certifying such a program.

The last part of my question is for Dr. L'Espérance. It's always nice to meet a neurosurgeon, particularly at this distance.

Voices: Oh, oh!

Hon. Stanley Kutcher: I'd just like your comment on a comment we heard earlier: When a person feels they are a burden on the family, their "autonomy is gone". Would you agree that because you feel a burden to your family, you lose your autonomy as a human being?

[Translation]

Dr. Georges L'Espérance: I don't think one can say that a patient had lost their autonomy. I'm not sure what basis one could use to say that.

On the other hand, I'd like to repeat the words used by Dr. Marcel Boisvert, a geriatrician and a compassionate doctor, who said that even if someone very old tells us that they no longer want to be a burden to their family, what's pathological about saying that?

It could very well be an altruistic, completely acceptable, and very interesting reaction. Of course, it's important to take into account the fact that such patients are treated over a very lengthy period. You don't decide from one day to the next when you get up in the morning that you're going to make an advance request for medical assistance in dying.

I trust that answers your question.

[English]

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

Is that it, Senator Kutcher?

Hon. Stanley Kutcher: I think I'm out of time, Chair.

The Joint Chair (Hon. Marc Garneau): Yes, you're just about there.

For Mr. Bach, this is just to note that Senator Kutcher made reference to something that you said about stigma being a driver, so we will follow up with you. He is asking for more corroboration and elaboration on that statement you made, but we'll follow up with you after this session.

We'll now turn to Senator Dalphond.

[Translation]

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

My question is for Dr. L'Espérance.

Unfortunately, we don't yet have access to your brief. However, I read the brief from your association, which you tabled in the National Assembly last month, and in which you had made a proposal to have criteria and requirements for advance directives. I presume that you are still of the same opinion that is mentioned in this brief.

And you added:

It is worth emphasizing once more that the availability of [medical assistance in dying] prior to advanced cognitive deterioration provides serenity and peace of mind, and enables these people to live life to the fullest and enjoy precious moments for a time, without the anguish of a lengthy period of suffering and loss of dignity as death approaches.

Is that based on your experience? If so, could you tell us about it?

Are there any statistical data to support this claim?

Dr. Georges L'Espérance: There are no statistics to my knowledge. Let's say that it's our joint experience, meaning the experience of virtually every doctor who provides medical assistance in dying.

The experience acquired is from being with patients who have received a diagnosis of a cognitive neurodegenerative disease, and with whom we proceed to medical assistance in dying after three months, six months or a year. They can obtain medical assistance in dying for as long as they are capable of deciding. When that point is reached, they lose months or years of life.

But the fact of knowing, particularly since March 2021, that they will not have to undergo this slow and painful process, gives them a form of serenity. I've seen patients arrive at the hospital to receive medical assistance in dying wearing a tie, holding flowers and smiling. All doctors who provide medical assistance in dying know about this experience with patients, by which I mean the knowledge that things will end calmly and serenely without any anxiety. There are also patients suffering from very recent illnesses, including cancer. As for Alzheimer's disease, we have all had this kind of experience.

Hon. Pierre Dalphond: As it stands, the wording of the act says that if a person cannot provide advanced directives, they choose medical assistance in dying and, in a sense, die prematurely.

Dr. Georges L'Espérance: That's what the whole debate is about. These people can lose weeks, months and even a year or two of a very pleasant and very interesting life with their families. When people lose their decision-making capacity, they can no longer receive medical assistance in dying, and that's the reason for the study in progress. It's why we are here this evening.

Hon. Pierre Dalphond: Thank you, Dr. L'Espérance.

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

[English]

We'll go now to Senator Wallin.

Hon. Pamela Wallin: Thank you very much.

I'd like to hear from Dr. L'Espérance and Dr. Andrew. I want to have comments from both of you. I'll make my point and have you respond to it and agree or disagree.

I want to follow up on the comments made by Madame Vien, another of our colleagues, on the catch-22 that we find ourselves in when it comes to dementia or Alzheimer's. Some witnesses have argued that you need a diagnosis for an advance request, but once you are diagnosed, you are then, by definition, considered incompetent. That's the bind that people find themselves in.

I think we heard testimony here that an advance request does not equal informed consent, when in fact that's exactly what it is. You're making that request in advance when you are still competent.

Could I have both of you speak to that issue? You'll probably have about a minute each.

[Translation]

Dr. Georges L'Espérance: I'll take a few seconds to answer before giving the floor to Dr. Andrew.

These days, patients who receive a diagnosis of a neurodegenerative disease or dementia can get it as long as they still have decision-making capacity. Why? Because they are asking why they are experiencing judgment, memory, and other problems. So they consult their doctor, who makes a diagnosis.

Some patients are definitely capable of deciding, just like people who are perfectly capable of driving their car and going about their business.

I believe that a diagnosis is essential. There is no contraindication.

I will now give the floor to Dr. Andrew.

[English]

Hon. Pamela Wallin: I agree with that totally. It was represented by others in a different way. Thank you.

Go ahead, Dr. Andrew.

Dr. Melissa Andrew: I totally agree that the diagnosis does not necessarily mean incapacity. That's a separate question and would happen later.

I would add the important point that in some places, unfortunately, we lack access to diagnosis. Some people, unfortunately, get a diagnosis quite late in their journey, even if they were trying to get it earlier. That speaks to the need for our system of dementia care to be strengthened.

Hon. Pamela Wallin: It's as if informed consent is becoming a question of timing, depending on where you live and the nature of the progression of your individual disease.

Dr. Melissa Andrew: That's an interesting point. Yes, if you require a diagnosis, it relies on the diagnosis having been made early enough, and all of the education that would go along with making these decisions being done early enough, before the lack of capacity occurs.

Hon. Pamela Wallin: Go ahead, Dr. L'Espérance.

[*Translation*]

Dr. Georges L'Espérance: For the various forms of dementia, what's involved is a relatively slow process for the vast majority of patients. It's spread over several years. There may be locations, in the far north for example, where it may be more difficult to obtain a diagnosis, but that has not been our experience, even though the health system may not always be adequate. In fact, people get their diagnosis and in a year or two they can have a consultation. Family doctors today are generally very good at diagnosing neurodegenerative diseases.

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

[*English*]

Thank you, Senator Wallin.

We'll now go to Senator Martin.

The Joint Chair (Hon. Yonah Martin): Thank you to all of the witnesses this evening.

I have one question for Mr. Bach.

What is the difference between an advance medical directive for medical assistance in dying and an AMD for withholding life-saving treatment? I know we've been hearing various responses. If we have one, why not the other?

Mr. Michael Bach: I think they're quite different.

Advance requests or directives for withholding treatment are about things that aren't going to be done to us. All of the examples listed earlier by Dr. Andrew were about things that you refuse to have happen to you. We've provided for that under provincial-territorial law on the basis that by refusing certain things, you do exercise control in the sense that you will allow your death to take its natural course.

In the case of providing advance requests, I would still submit that there is no consent to the termination of your life at a future point. There is a substitute decision-maker who has to decide that now is when we'll do the injection. You're not consenting; someone else is, and it is to have something done to you that is intended to cause your death. That is fundamentally different from advance directives for withholding or withdrawing life-sustaining treatment, at which time comfort care—palliative care—is provided to support

you through the natural course of your death. Those who provide that comfort care and withhold those treatments do so guided by your advance directive and on the decision of a substitute decision-maker at the time—I'm sure many around the table here have been in these decisions—that now is the time to withhold that treatment so that their son, brother or father can pass.

They're fundamentally different. I think collapsing or blurring the line between them leads down a path that puts one of the most vulnerable minorities in this country at risk. What is a democracy, after it all? It protects the rights of minorities. The minority I'm talking about is people with dementia who cannot consent and do not have capacity to consent, or people with intellectual disabilities who do not have the capacity to consent to their death.

That's the group we're protecting here. It's not those who can make advance requests. The group that we're talking about here is the group who cannot consent. They don't have the capacity to consent to a proactive intervention on the part of a medical professional intended to cause their death.

In this democracy, are we protecting one of the most vulnerable minorities in our society? I think the proposals that are advocating adoption clearly do not meet the test of protecting the right to life of one of the most vulnerable minorities in our society.

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

That will bring our panel to a close.

On behalf of the committee, I would like to thank Dr. Andrew and Mr. Bach.

[*Translation*]

I'd also like to thank Dr. L'Espérance.

Thank you all for your testimony. It's on a very complex, difficult and sometimes emotional subject, as you all know. We are very grateful to you for having given us the benefit of your expertise on this committee.

[*English*]

With that, fellow members and witnesses, this meeting is adjourned.

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