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# Special Joint Committee on Medical Assistance in Dying

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





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• (1830)

[Translation]

**The Joint Chair (Hon. Marc Garneau (Notre-Dame-de-Grâce—Westmount, Lib.)):** Good evening, everyone.

Welcome to the 22nd meeting of the Special Joint Committee on Medical Assistance in Dying.

I would like to begin by welcoming members of the committee, the witnesses and those watching this meeting on the web.

My name is Marc Garneau and I am the committee vice-chair from the House of Commons. With me this evening is the Hon. Marie-Françoise Mégie, the committee vice-chair from the Senate.

[English]

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

I'd like to remind members and witnesses to keep their microphones muted unless recognized by name by the chair. All comments should be addressed through one of the chairs. When speaking, please speak slowly and clearly.

Interpretation in this video conference will work like in an in-person committee meeting. With the interpretation button, you have the choice, at the bottom of your screen, of floor, English or French.

With that, I would like to welcome our witnesses for panel one. They are here to discuss advance requests.

As an individual, we have Adelina Iftene, law professor.

[Translation]

We also have with us, by videoconference, Dr. David Lussier, geriatric physician, and Dr. Félix Pageau, geriatrician and researcher.

Thanks to the three of you for joining us.

First, we will hear the opening statement of Ms. Iftene, followed by those of Dr. Lussier and Dr. Pageau.

[English]

Ms. Iftene, you have the floor for your five-minute opening statement. Please go ahead.

**Dr. Adelina Iftene (Associate Professor, Schulich School of Law, Dalhousie University, As an Individual):** Honourable members of the joint committee, thank you so much for the invitation to make a submission before you today.

As I mentioned in my correspondence with the committee clerk, my expertise is actually not in advance directives or MAID generally. Rather, it is in corrections, health care law and policy for incarcerated people and issues surrounding decarceration. Hence, my comments today pertain specifically to the issues raised by the implementation of MAID—

[Translation]

**Mr. Joël Godin (Portneuf—Jacques-Cartier, CPC):** On a point of order, Mr. Chair, there is no interpretation.

[English]

I'm sorry, Professor Iftene.

[Translation]

**The Joint Chair (Hon. Marc Garneau):** I see.

[English]

We'll hold for a second. We're not getting the proper translation.

Mr. Clerk, let me know when the translation is provided so that we can continue.

[Translation]

**Mr. René Arseneault:** Mr. Chair, we're being told the interpretation seems to be working now.

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

[English]

Ms. Iftene, I think we've resolved our translation problem. Please continue.

**Dr. Adelina Iftene:** My expertise is not in advance directives generally or in MAID broadly, but rather in corrections, health care law and policy for incarcerated people and issues surrounding decarceration. So my comments today pertain specifically to the issues raised by the implementation of MAID in prisons, issues that should be prioritized in the review of the MAID legislation.

The conversation so far around MAID in prisons has largely been reduced to dichotomy solutions. Should incarcerated people have access to MAID? Should the MAID procedure take place in the correctional institution or should it take place somewhere in the community?

I want to be clear. To the extent to which and in the circumstances in which MAID is a health care service in Canada, based on the nationally and internationally protected principle of equivalence of care, it must also be available in the same conditions to people who are incarcerated. However, this answer oversimplifies matters, and it does so because the questions it answers entirely miss the point of the problem of illness and death in prison.

It is well known that health care in prisons—basic care, specialized health care and especially palliative and long-term care—is deeply inadequate and often fails to meet any community standard. I, and others, especially the Office of the Correctional Investigator, have long documented the systemic health care inadequacies, and I don't think these can be the subject of a reasonable, informed debate any longer.

It is also clear that Canada does not have a functional compassionate release mechanism. Section 121 of the Corrections and Conditional Release Act, the parole by exception provision, has been used 20 times over 10 years prior to the COVID pandemic, and it cannot generally be used for those serving life sentences. At the same time, during the same period of time, 30 to 40 people have died annually of natural, expected death in prisons. The use and availability of section 121 has not improved in light of the implementation of MAID in prisons a few years back.

The reality is that in a country where there is no death penalty and no life sentence without possibility of release, the number one cause of death in prisons is natural death occurring at the end of an often known illness for which the individual had limited, if any, adequate treatment options.

If the only consistent and realistic option for this suffering is MAID, Canadian sentences are becoming de facto death sentences. It is unacceptable that it is easier to obtain MAID when one is in custody than to obtain any type of compassionate release.

For instance, a person serving life is not eligible to even apply for parole by exception unless they are within weeks of dying. That, we know, is not the case with MAID. For a discussion on this issue, as well as for a discussion on compassionate release and the way it works in Canada, I would like to draw your attention to the articles I have written or co-written with Professor Jocelyn Downie, which I have submitted to you in advance.

The issue with the fact that there is easier access to MAID than to release is not, I submit, with MAID. Simply prohibiting MAID for those incarcerated or making it harder to access is not a solution to the lack of choice, dignity and autonomy of those in prison, and it is also inconsistent with the equivalence of care obligation. Letting people suffer is not enhancing their dignity or autonomy.

The problem is not with MAID being available to prisoners. The problem is with the lack of adequate release mechanisms and supports. Everyone who has a serious, life-limiting illness or who is in intolerable suffering should be eligible for consideration for some working form of compassionate release. Compassionate release needs to be available not just so the individual can receive the MAID procedure in the community but so they can make all end-of-life decisions in the community, whether those include MAID or not.

The discussions about the substantial reform of release mechanisms—which includes eligibility to be considered for release, the factors that are relevant to the release decision and the expertise of the parole members on these issues—are all discussions that are inherently linked to the broader discussion on the implementation of MAID in prisons.

Meaningful amendments to the MAID legislation must consider those in custody and, as a result, they will have to ensure that people in custody have realistic options for release to community, where they can freely make informed end-of-life decisions.

To conclude, I would like to mention that there are a number of outstanding issues with MAID, in addition to the issue of a lack of other options, including palliative care and release. These include the Correctional Service's exemption from reviewing and investigating MAID death, which is linked to a lack of adequate oversight, and the role prison physicians have in the assessment process. I would be happy to address those issues during the question period.

• (1835)

Thank you.

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

We'll now go to our second witness.

[*Translation*]

Dr. Lussier, you have the floor for five minutes.

**Dr. David Lussier (Geriatric Physician, As an Individual):** Thank you, Mr. Chair.

Thank you for the invitation to come and discuss this important topic with you.

I will begin with a brief introduction.

I am a geriatric physician at the Institut universitaire de gériatrie de Montréal, which is part of the Centre intégré universitaire de santé et de services sociaux du Centre-Sud-de-l'Île-de-Montréal. I have had additional training in pain and palliative care. For the past 20 years or so, I have practised almost exclusively at a chronic pain management clinic for the elderly.

I have been interested in medical assistance in dying since it first became a topic of discussion in Quebec. Although I am a member of Quebec's Commission sur les soins de fin de vie, I wish to point out that I am not speaking here on its behalf, but rather as an individual.

I practise medical assistance in dying, on average, once or twice a month, in some instances for patients whom I have been following for a very long time and in others for patients for whom I have been asked to consult on this specific care. Given my clinical expertise, I normally assess people whose eligibility is unclear or whose natural death isn't reasonably foreseeable. Some of those persons suffer from major neurocognitive disorders.

I also lecture regularly on medical assistance in dying to health professionals and the general public.

Today, I would like to discuss the most important points regarding advance requests for medical assistance in dying for persons with a major neurocognitive disorder.

First, I obviously can't comment on the opinions of Canadians across the country. However, I can rely on the testimony given to the special parliamentary committee of the National Assembly of Quebec last fall and on comments I have gathered during my lectures on the subject and in my practice. Based on that information, I believe there is fairly broad acceptance of advance requests in Quebec in the general population and among persons with major neurocognitive disorders and their loved ones. There is also fairly broad acceptance among health professionals, even though some anticipate implementation issues. Consequently, the Quebec public expects that medical assistance in dying can be made possible by advance requests, and many individuals were greatly disappointed when the bill on this topic had to be abandoned in the spring.

In the present circumstances, since the criterion of reasonably foreseeable natural death was removed, persons suffering from major neurocognitive disorders may be eligible for, and may receive, medical assistance in dying. There is a brief period in disease development where the disorder is grievous enough that it causes advanced and incurable decline in capacity but not yet grievous enough to compromise the patient's ability to request medical assistance in dying. In my experience, persons with a major neurocognitive disorder who request medical assistance in dying wait as long as possible before doing so. In many instances, they do it just before losing that ability, such that, in some instances, the 90-day period must be shortened because loss of capacity is imminent. If they could make an advance request, many of them would probably choose not to request medical assistance in dying at that time so they could continue enjoying happy moments with their loved ones. Consequently, they die sooner than they would have wished. In that sense, it can be said that their right to life, guaranteed under section 7 of the Canadian Charter of Rights and Freedoms, is thereby violated, as the Supreme Court held in the Carter judgment, since, in order to be granted access to medical assistance in dying and not to deteriorate until the end, those persons must die earlier than they would have wished.

I therefore believe that the act should be amended to allow advance requests for medical assistance in dying for persons with major neurocognitive disorders. This is nevertheless a very complex issue from both ethical and implementation standpoints. First of all, it is very difficult to assess suffering, which is, by definition, the subjective experience of a person incapable of communicating it. In some cases, there is undeniable objectifiable suffering, accompanied by non-verbal signs of pain and psychological and behavioural symptoms associated with dementia, such as aggressiveness. In other cases, which are, rightly or wrongly, called pleasant dementia cases, patients are happy in their day-to-day lives despite their cognitive disorders and loss of autonomy. However, if they had seen themselves in that state, they might not have wanted to live. Should the eligibility criterion be contemporaneous suffering or anticipated suffering? That's an important and complex question.

Another important question arises regarding the situation in which the individual making an advance request refuses to cooperate when the time comes to administer medical assistance in dying. At an advanced stage, many individuals resist all contact and treatment and become aggressive when touched. As a result, they reject attempts to insert any intravenous device without previously being sedated or restrained. Even though patients, when they were competent, probably wanted to be sedated or restrained for the purpose of administering medical assistance in dying, are we to disregard their verbal or physical refusal when they are no longer competent? Many clinicians say they would find it very difficult to do so, especially if patients showed no signs of objectifiable suffering.

In short, I think that the act should be amended to allow a person to make an advance request for medical assistance in dying. However, the guidelines and practice guides should be very clear in order to support clinicians who are involved when medical assistance in dying is requested or administered.

● (1840)

**The Joint Chair (Hon. Marc Garneau):** Thank you very much, Dr. Lussier.

We will now continue with Dr. Pageau.

Dr. Pageau, you have the floor for five minutes.

**Dr. Félix Pageau (Geriatrician and Researcher, As an Individual):** Good evening.

I'm a physician, an ethics researcher and geriatrician. I know Dr. Lussier well, but I don't agree with his position and I will explain why.

First of all, I must say that I am grateful to be taking part in the committee's work once again. In my last appearance, I discussed somewhat more philosophical and ethical contexts. Today I will be talking about a slightly more practical context.

I am aware that a physician is responsible for respecting a patient's autonomy. Of course, the principles of good treatment and non-maltreatment must be applied. The government must protect vulnerable people and protect people from themselves. Which is why it has established a legal age for alcohol consumption and requires people to wear seat belts in cars and helmets on motorcycles. Freedom of autonomy is therefore not absolute in Canada; it is regulated.

I have three arguments to advance and points to clarify. Time permitting, I will also make some recommendations.

My three arguments focus on the following elements: the error that individuals make when drafting their advance directives regarding medical assistance in dying, the error made by individuals who apply those directives, and the societal issues associated with medical assistance in dying by means of advance requests for people suffering from major neurocognitive disorders.

With respect to the error made in drafting advance requests, the problem stems from the fact that people don't have a crystal ball in which they can see the future absolutely clearly. Autonomy must apply in the present and cannot be anticipated. One must also consider with whom will those advance directives be made. Will it be with a specialist in dementia or major neurocognitive disorders, in this instance a geriatrician, a geriatric psychiatrist or a family physician who sees many such patients? It will be necessary to open medical assistance in dying clinics. Do we have the necessary resources? Is there a risk that the physician take a paternalistic approach to providing expertise to these patients? Autonomy would not be fully respected in that instance.

The changing self is another known argument, according to which significant moments in life, such as receiving a diagnosis of major neurocognitive disorder, alter an individual's personality. Families often tell us they no longer recognize a loved one who has received that kind of diagnosis. Those individuals aren't who they used to be. So a major change occurs. Is what a person said 20 years ago still valid today when he or she is proceeding with medical assistance in dying?

Furthermore, those who implement medical assistance in dying directives may make a number of errors. First of all, every written text requires interpretation. Whatever is written, whether texts of law, literary texts or even text messages, must always be interpreted, especially if the person concerned isn't around to tell us exactly what he or she meant. That interpretation may result in a number of errors. It may turn out that the advance directives are not at all applicable. In that case, they will not be applied, which is thus a lesser evil. That moreover is what often occurs in the Netherlands. On the other hand, there is the danger that they may be applied excessively as a result of conflicts of interest among the physicians or among members of the family, whether out of a desire to receive an inheritance, to free up beds or to remove patients with major neurocognitive disorders from emergency departments. When the medical team and family decide instead of the patient, it isn't autonomy that prevails, but rather a form of paternalistic expertise.

Does a lack of refusal really constitute consent? People who simply say yes without understanding exactly what that implies don't really give their consent. This is something we often hear in hospitals. If, for example, a woman says she wants her uterus removed, should we do it? Has she truly understood? Advance directives do not solve this problem. Assent, even implicit, is not consent.

The societal argument is perhaps slightly more philosophical. We are talking here about "dementiaphobia", the fear of people who are mentally ill. The stigmatization of major neurocognitive disorders, and of associated behavioural and psychological disabilities and symptoms, is what causes this fear and leads people to project into the future. As a result of this form of discrimination, they don't want to become those people who have been abandoned.

I would now like to clarify a few points. First of all, medical assistance in dying is not the same thing as advance medical directives. There is indeed a difference between requesting a form of care, such as medical assistance in dying, and refusing care one considers futile. Furthermore, medical assistance in dying is not like withdrawal of treatment. As in the distinction among first-degree murder, negligence causing death and an accident causing

death, it is intentions that count, and intentions differ depending whether one is dealing with advance requests respecting medical assistance in dying or with withdrawal of treatment.

With respect to my recommendations, I believe that the government should protect the most vulnerable. It should also increase funding for work done to promote palliative, geriatric and geriatric psychiatric care. It should also improve access to that care by promoting essential jobs in those areas. Lastly, it should avoid "dementiaphobia" at all costs and avoid promoting it, contrary to what certain persons do who defend medical assistance in dying by means of advance directives.

• (1845)

**The Joint Chair (Hon. Marc Garneau):** Thank you very much, Dr. Pageau.

I now turn the chair over to my colleague Senator Mégie.

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie (Quebec, Rougemont), GSI):** Thank you, Mr. Chair.

I am Marie-Françoise Mégie, senator from Quebec and committee vice-chair from the Senate.

We will now begin the round of questions with Mr. Ellis.

[*English*]

You have five minutes.

**Mr. Stephen Ellis (Cumberland—Colchester, CPC):** Thank you, Chair.

Thank you to the other committee members for allowing me to be here and be part of this fascinating conversation.

Thank you to the witnesses for being here this evening as well.

Dr. Iftene, I wonder if you might clarify this, please. Are you asserting that, because the penal system has such terribly poor conditions and access to medical care, this is the reason why MAID should be a part of the prison system? I wasn't quite clear on what your point was.

• (1850)

**Dr. Adelina Iftene:** It is not because the penal system has poor conditions; it is because of a right that's called the equivalence of care. As a result, all health care services that are provided in the community must be available in prison. That is not the case, unfortunately. We know there is substandard health care provided in prisons, so my argument was that the solution.... Of course, there is no real systemic palliative care available. Again, all that lack is breaching the requirement for equivalence of care between prison and the community. Prohibiting MAID in prisons is just one more failure on that part. From that perspective, I think that from an international and national standard, we have to provide prisoners with all the health care services that are available in the community.

I think the conversation is more complicated when it comes to people in custody, simply because there are concerns regarding their ability to provide consent on a free basis. I think that as long as we do not have compassionate mechanisms working for individuals who are experiencing limiting life circumstances or intolerable suffering—which lots of times are also associated with a very significant decrease in risk—as long as we don't have these mechanisms that allow them the option to be transferred to the community to make end-of-life decisions there, this conversation is going to be very complicated. I think it does raise issues—

**Mr. Stephen Ellis:** Thank you, Dr. Iftene. I appreciate that.

Part of the difficulty, of course, then remains that without appropriate medical care in the penal system, moving on to adding things like MAID, to me, would seem to be somewhat difficult. Thank you for that.

I'll go to Dr. Lussier, if I may.

You talked about this obviously being very difficult, and I think your colleague Dr. Pageau perhaps brought some of the difficulties forward with respect to that. It would appear perhaps that you have different ideas. I wonder, Dr. Lussier, if you might comment on the length of time between making an advance directive and of course coming to that point in their life when it may be required. Are there difficulties with respect to that, sir? What safeguards might be needed to look at those things?

**Dr. David Lussier:** I think one of the safeguards has to be that you have to make sure that the person is aware of his or her diagnosis. This is why, for example, in Quebec, when this was discussed, it's always been said that it should be done after the person has been diagnosed with a major neurocognitive disorder. I today couldn't do an advance request for medical assistance in dying because I don't have any diagnosis for a neurocognitive disorder—so the person has to be aware.

The other safeguard would be that it would have to be reassessed. It would have to be reiterated several times in the process, so you can't just do it once and then it's applied or implemented five or seven years later. It would have to be reassessed and repeated several times to make sure that the person still wants the same thing.

**Mr. Stephen Ellis:** Thank you, sir.

Through you, Chair, to Dr. Pageau, are there any safeguards that you think would be beneficial here?

[*Translation*]

**Dr. Félix Pageau:** We have to make sure that people who have major neurocognitive disorders don't request medical assistance in dying merely because they're afraid of their own decline and want to avoid becoming a burden to their loved ones. That's often what we hear.

I'm somewhat concerned at the idea of a physician immediately proposing medical assistance in dying to a patient upon diagnosing a major neurocognitive disorder in a clinical setting. That might raise questions in the patient's mind; he might wonder whether the physician feels that his status is grievous enough for him to request medical assistance in dying. Imagine if I informed you that you

have diabetes and then asked you whether you'd like to opt for medical assistance in dying. You might think diabetes is a very serious disease.

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** Thank you, Dr. Pageau.

I now give the floor to Mr. Arseneault.

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

My first question is for Dr. Lussier and is along the same lines as the question my colleague Mr. Ellis asked.

Dr. Lussier, earlier you described it well when you said there is always a brief period following a diagnosis of neurocognitive disease when patients' minds and judgment are still intact and they can make a request for medical assistance in dying. Did I understand you correctly?

• (1855)

**Dr. David Lussier:** I was actually talking about the present situation. Yes, there is a moment when the decline is advanced and the disease is serious enough to be considered incurable. The person then meets the criteria. As a result, some people with neurocognitive disorders are currently receiving medical assistance in dying. That's already being done. There are many cases every year.

**Mr. René Arseneault:** Can you suggest any safeguards for those cases in particular. In your view, could we further improve that; could we be more cautious, or are the current safeguards appropriate?

**Dr. David Lussier:** Regardless of who has access to medical assistance in dying, we will always have to ensure that it is never requested for lack of appropriate treatment. Medical assistance in dying should never be chosen because patients suffering from a neurocognitive disorder don't have access to treatment appropriate to their condition. This currently applies in all cases, whether they involve cancers, physical disease or neurocognitive disorders. Consequently, we must ensure that patients are accurately diagnosed, that they are well supported when they request medical assistance in dying and that their request isn't made lightly for lack of other treatment.

**Mr. René Arseneault:** Those are obviously the safeguards we must aim for.

I don't work in the health field, but we've heard from many witnesses on this matter over a long period of time, and I don't believe I've ever heard anyone tell us about a patient who hadn't received adequate care and to whom medical assistance in dying had been suggested as a solution.

Have you seen that situation in your practice?

**Dr. David Lussier:** No, I haven't seen it in my professional practice, and nothing in anything I have heard in the various forums suggests that medical assistance in dying has been requested for lack of proper treatment. Furthermore, palliative care statistics show that the vast majority of people who have requested medical assistance in dying have previously had access to palliative care. If we want to extend that option to others, we only need to ensure that remains the case.

**Mr. René Arseneault:** Thank you, Dr. Lussier.

Dr. Pageau, I'll continue along the same lines.

In your experience as a physician, have you ever witnessed situations in which patients were informed that there were no doctors available to provide treatment appropriate to their condition and medical assistance in dying was offered to them if they wished to have it?

**Dr. Félix Pageau:** Yes. People will often say they don't want to be a burden. They aren't being given adequate psychosocial care...

**Mr. René Arseneault:** I have to interrupt you because I don't have a lot of time. I'm not talking about the patient's point of view, but rather about yours as a health professional. Have you seen professionals administer medical assistance in dying in such cases?

**Dr. Félix Pageau:** Yes, a contentious case came up in the research I conducted for my master's degree.

**Mr. René Arseneault:** So it was a case that you studied as part of your master's program. Is that correct?

**Dr. Félix Pageau:** Yes, there was at least one case.

**Mr. René Arseneault:** Do you have any statistics that might show us that this is a common practice or that it has occurred many times?

**Dr. Félix Pageau:** Yes. According to Quebec data, one of the primary reasons why people request medical assistance in dying is that they feel they aren't getting appropriate services or treatment.

**Mr. René Arseneault:** I understand that. You're talking about the patient's perception. I'd like to know the the health professional's point of view.

We've heard a lot of professionals talk about safeguards and all that. Correct me if I'm wrong, but I don't get the impression that health professionals, regardless of the province they live in, have told patients that there are no specialists to treat their condition and that, consequently, if they want medical assistance in dying, they could administer it to them.

I want to know the profession's stance on this. Have you seen your peers administer medical assistance in dying because there were no other available treatments?

**Dr. Félix Pageau:** Yes, and, as I told you, it's very insidious. Professionals agree to practise medical assistance in dying as a result of a lack of resources.

**Mr. René Arseneault:** Is that a known fact within the profession?

**Dr. Félix Pageau:** We're seeing that social suffering is one of the more frequent reasons given for requesting medical assistance in dying. Physical pain is cited in less than 1% of cases. Psychological suffering represents a very small percentage as well. It's often social suffering and other factors that are mentioned. People won't say it the way you said it because there's a certain lack of sensitivity...

**Mr. René Arseneault:** I apologize for interrupting, Dr. Pageau, but I only have five seconds left.

Would you please send your master's thesis to the committee clerks?

**Dr. Félix Pageau:** Yes.

**Mr. René Arseneault:** Thank you very much.

Thanks to all the witnesses.

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** Thank you very much.

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

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

Dr. Lussier, you mentioned the right to life in connection with the Carter judgment. One might even say that the Baudouin judgment also presents the argument that people are obliged to end their lives prematurely by suicide.

When you inform patients that they have a major neurocognitive problem, do you then ask them in the same breath, as Dr. Pageau said, if they want medical assistance in dying!

● (1900)

**Dr. David Lussier:** Obviously, no. It wouldn't be possible to do that in the present circumstances because a person's capacities must be in advanced decline for that person to be eligible for medical assistance in dying.

When you make a diagnosis, you usually ensure that the person has made a will and a mandate in case of incapacity. You ensure that the person has made all the necessary arrangements for the disposition of his or her person and property. However, you won't bring up medical assistance in dying in the same breath or during the same meeting.

There's a major debate within the medical profession on this particular point: should we propose medical assistance in dying, as one of a number of therapeutic options, to someone who's clearly eligible, or do we refrain from doing so? There's no consensus. I think we should wait for the request for medical assistance in dying to come from the person rather than propose it as a therapeutic option. That position is can be criticized, but it's mine.

**Mr. Luc Thériault:** In your practice, do patients often start a discussion of medical assistance in dying? Everyone wants to live as long as possible, although without going beyond the threshold of what's personally considered tolerable.

**Dr. David Lussier:** In my case, it's always the patients who bring up medical assistance in dying. Many of my patients who have neurocognitive disorders or other pathologies tell me they want to die. Many will ultimately decide not to request medical assistance in dying. Some discuss medical assistance in dying merely to express the fact that they want specific treatment for a particular problem. Some will go so far as to request medical assistance in dying, but it always comes from them.



What I meant to say earlier is that people want to wait as long as possible, until the very last minute, before requesting medical assistance in dying. In some cases, they won't say it's time until they think they're completely losing their mind. They think that, if they wait another two or three months, they'll probably lose their capacity and will no longer be able to obtain medical assistance in dying. If they could make an advance request, that would relieve this distress and concern, and they'd be able to continue living longer.

**Mr. Luc Thériault:** Even if a person solemnly designated a third party at a meeting held for that purpose and specified when he or she wanted medical assistance in dying to be administered, the fact remains that the process is spread over time and must therefore include a reassessment measure, as you mentioned. Meetings must be planned throughout the patient's journey to reassess the situation until the designated third party ultimately asks the attending team to assess the loved one's condition. There have to be repeated assessments.

In your experience, how many of these kinds of stages must there be? Is this done on a case-by-case basis?

**Dr. David Lussier:** That's very hard to say because it depends on how the disease develops. We often cite the example of Alzheimer's disease, which is a gradual deterioration of capacity, but there are other neurocognitive disorders where the deterioration won't be as gradual. It's impossible to predict. It may last many years or only one or two years, as in the case of fast developing dementias.

**Mr. Luc Thériault:** In your experience, in the case of pleasant dementias, isn't the third party ultimately the key person in the situation? If the third party doesn't start the process or request that the attending team start assessing...

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** I apologize for interrupting, Mr. Thériault, but your time is up.

• (1905)

**Mr. Luc Thériault:** I thought everyone would consider that relevant, Madam Chair.

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** Someone else may have an opportunity to come back to it.

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

[English]

**Mr. Alistair MacGregor (Cowichan—Malahat—Langford, NDP):** Thank you.

I'll direct my questions to Dr. Pageau.

In your opening remarks, you hit on two items.

First, there can be problems with errors in interpreting the written instructions from a patient, especially when that patient has lost capacity to help someone interpret what they originally meant. You also mentioned there is a stigma associated with dementia. I want to ask you about those two points, because we've had previous witnesses who said there ought to be a requirement for objectively assessable criteria, which can be very clearly understood: for example, "When I reach a certain stage in dementia, this is what I would like to happen."

I understand that there is a stigma out there against Alzheimer's. It's not very clearly understood. However, to take a different side, is it not paternalistic of us to assess someone's feelings about dementia, especially if that person once lived with a family member who had dementia, understands the disease intimately, and also understands what is coming their way?

I'd like to hear your feedback on those two points, please.

[Translation]

**Dr. Félix Pageau:** Yes, it's a matter of interpretation. The third party must initiate the request, as was previously mentioned. The physician must then determine whether it's valid and will then examine what the patient has written.

The cited criteria are often incontinence and inability to recognize family. However, those criteria may emerge early in the development of the dementia, but the person may nevertheless be happy. Some people don't want to use the term "dementia" because they consider it so pejorative. That shows you how much "dementiaphobia" there is in society.

My colleague mentioned the discomfort that may be felt at the idea of suggesting medical assistance in dying and the fact that we sometimes prefer to wait for the patient to request it. When one of my patients has an infection, I don't wait for him to ask me for antibiotics; I know that they're the appropriate treatment and therefore suggest it. The patient may then decide whether to accept it. When I know that a treatment is right, I propose it without waiting to be asked.

It's interesting to note this discomfort over medical assistance in dying. If physicians wait for patients to request it from them, that may be because they aren't comfortable proposing it. The discomfort may also be exacerbated by "dementiaphobia". The word "dementia" is so frightening that some people in the United States have decided to call it a "major neurocognitive disorder". The stigmatization associated with dementia is known and present.

When an individual reaches an advanced stage of dementia and the medical team attempts to determine whether the patient's inability to recognize his or her loved ones constitutes sufficient suffering to warrant medical assistance in dying, they may potentially be relying on "dementiaphobic" criteria.

[English]

**Mr. Alistair MacGregor:** Thank you.

I'd like to turn my next question to Professor Iftene.

Thank you for sharing your perspective on the experience inmates have in our federal prisons, which I don't think has often been talked about. Over the summer, I got to visit two of our federal institutions in British Columbia. That was a big learning experience for me.

You centred a lot of your remarks on the substandard medical care available to inmates in federal institutions. For patients who might be in a maximum-security prison, serving time for a very serious crime—we're talking about life imprisonment—when those patients start exhibiting symptoms of dementia and are obviously unable to comply with a regular prison routine, or even interactions with guards or other inmates, how do they progress, generally? Do they go to a lower-security facility?

Could you talk a bit about inmates who are diagnosed with those neurocognitive disorders and start exhibiting some of those symptoms?

**Dr. Adelina Iftene:** It's very difficult. Many times, in prisons, dementia and other major cognitive impairments are misdiagnosed, because first responders tend to be officers. They obviously do not have any expertise in this. Even the prison physician, who might have access to seeing these people, does not have the expertise necessary to diagnose these issues.

What we end up seeing, many times, is people who may have had dementia for a number of years, but who were misdiagnosed as having alcohol withdrawal. That's a very common thing we see, or having behavioural issues, misbehaving and being sent into various [*Inaudible—Editor*]. Now it's structured intervention units, but it used to be solitary confinement, or other things like that.

In fact, I've seen people with dementia moved from minimum-security institutions, because they were serving life, not because they're—

• (1910)

[*Translation*]

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** I apologize for cutting you off, but that's all the available time you have.

I now turn the chair over to Mr. Garneau.

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

We will now go to questions from the senators.

I give the floor to Senator Dalphond, who has three minutes.

**Senator Pierre Dalphond:** Thank you.

My questions are for Dr. Lussier.

As I understand it, in your view, if we adopt a system that permits advance directives, a diagnosis must be made and an incurable disease must exist. There has to be a finding.

**Dr. David Lussier:** Yes.

Incidentally, I'd like to correct what you said, if I may. I prefer to say "advance requests" instead of "advance directives". It's an important distinction.

**Hon. Pierre Dalphond:** You're right: it's an advance request.

You discussed what happens when someone makes an advance request. The medical act will occur later. End-of-life care will be administered when the person no longer has the capacity to consent.

Right now, as a result of the amendments we've made, can people suffering from an incurable disease and whose death is imminent receive medical assistance in dying, even if they no longer have the capacity to consent to it, whereas they had that capacity at the time of the request? It would then be administered to them all the same. However, it wouldn't be possible to administer assistance to them if they showed signs of resistance. Is that what you'd recommend should be applied in response to the advance request? The moment a patient exhibited resistance, assistance in dying would not be administered.

**Dr. David Lussier:** It's much more complicated in an advance request case. Patients who have cognitive disorders often resist everything. They may object to baths, getting dressed or brushing their teeth. In that case, I'm not sure resistance to treatment can be interpreted as a refusal of treatment. The question is far more complex in cases where individuals have cognitive problems.

I think we have to try to find a compromise between administering that care by force to a person who demonstrates physical refusal and cancelling the request that person has made. A compromise may be possible.

When patients make an advance request, they could specify in advance that they want the care to be administered even in the event of refusal, or that they prefer that the care not be administered to them in the event of refusal. I believe that could be a compromise. This dilemma could be resolved by the patients when they make their advance requests.

**Hon. Pierre Dalphond:** Right now, under the path one system, you immediately stop the process if there's resistance.

**Dr. David Lussier:** Yes. However, that's not the same thing. People who are reaching the end of their lives and who lose their capacity are often unconscious. Resistance is less frequent. The person will be unconscious and therefore won't resist. That person won't be aware of his or her environment. It's not at all the same thing with persons...

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** Thank you, Dr. Lussier. I apologize for cutting you off. We have only three minutes.

**The Joint Chair (Hon. Marc Garneau):** Fine. I now give the floor to Senator Mégie for three minutes.

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** My question is for Dr. Pageau.

You mentioned an error made by the person completing the MAID request form. It seemed to me that it was the person who made the request but that the form was completed by a health professional assisting or accompanying the patient. What kind of error do you think that was?

• (1915)

**Dr. Félix Pageau:** It's the error of misguided autonomy. There has to be autonomy.

I can say at I want to buy a desert island in 10 years and wind up alone in a house, but, in the end, I have a large family and friends. Will I really want to live out my life alone on a desert island?

Perhaps my example's somewhat ridiculous, but we don't know what the future holds for us. Can we really anticipate dementia and the kinds of symptoms and psychological behaviours associated with it? People who think they can should provide some compelling evidence to confirm it. We don't know the future when a diagnosis is made. We don't know when the dementia will be advanced.

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** Thank you.

My second question is for Dr. Lussier.

With respect to safeguards, some witnesses have told us that, if someone makes a request for medical assistance in dying at some point in his or her life, that request should be reviewed or reassessed after a certain amount of time.

What's your opinion on that, and how frequently do you think the request should be reassessed?

**Dr. David Lussier:** It's actually difficult to determine the frequency because we don't know how much time will elapse between the two. I also think it would be important to reassess the request, as Dr. Pageau said, when he talked about the "changing self". I don't use philosophical terms as refined as his, but he said that our self, or one's self, evolves over time. Consequently, we must let the self of persons suffering from a cognitive disorder evolve as well. We can't deny them that right.

That's why it's important to reassess requests frequently in order to ensure that patients haven't changed their mind. Some ultimately adapt to their condition or, for example, to long-term care. They may adjust to a different life and no longer want medical assistance in dying.

Consequently I can't specify an interval or number of times, but it would be important to reassess the request every time it's made to ensure that the needs have not changed.

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** Thank you very much.

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

You have 13 seconds left, which is not enough time for another question. However, we have enough time for a second round of questions.

Senator, I turn the chair over to you for the second round.

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** Thank you, Mr. Garneau.

Mr. Ellis, the floor is yours.

[*English*]

**Mr. Stephen Ellis:** Thank you, Chair. I appreciate that.

Thank you again to the witnesses.

I have a couple of issues. I'll start with Ms. Iftene, if I may. I may cut you off. I'll try to be gentle with it.

You talk about misdiagnoses in the prison system, which I think does present a unique scenario in terms of how certain behaviours may be perceived. Have you ever thought about safeguards that may be required, should this be a decision made for the penal system?

**Dr. Adelina Iftene:** Absolutely. The first safeguard is to make release mechanisms and other options available. We cannot divorce that discussion. As long as there aren't viable release mechanisms, it's going to be very difficult to safely implement MAID in prisons. That's not a question. There have to be other options.

I'm not not in support of MAID. I'm not in support of MAID by itself. The first safeguard is that there have to be options and there has to be oversight.

I am very concerned about the lack of oversight that is currently associated with how MAID is implemented and the fact that there is no review of the MAID cases. CSC has no obligation to conduct mortality reviews and there don't seem to be any kinds of experts on the parole board to discuss other options when someone applies for release.

**Mr. Stephen Ellis:** Thank you very much for that. I appreciate your brevity.

Dr. Lussier, our colleague, Mr. Arseneault, talked a bit about the improper care given in certain diagnoses. I believe that all of us have heard the case of a veteran of Canada being offered MAID in what would appear to be a significantly inappropriate case, without access to mental health support. That's certainly something to consider.

You talked a lot about the difficulty in judging if people with dementia or other kinds of neurocognitive decline have capacity. Is this going to be left to an individual basis all the time, or is it going to be left to all individual physicians to help make that decision? That becomes very difficult.

Again, I'll come back to that. You did speak briefly about safeguards. What safeguards do you think we need to have in place for advance requests?

● (1920)

**Dr. David Lussier:** I think we have to make sure the advance request is done with a person knowing what they are requesting and make sure they know all the options available. We have to make sure that when or if they are implemented, they are done in the proper way and that we have a review system to make sure there is good medical care and good implementation of the advance request.

I think these are the main safeguards we have to put in place.

[*Translation*]

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** Thank you, Mr. Ellis.

Mr. Anandasangaree, you have the floor for three minutes.

**Mr. Gary Anandasangaree (Scarborough—Rouge Park, Lib.):** Thank you, Madam Chair.

[English]

This is for Professor Iftene.

I'm just wondering if you could walk us through the process for someone wanting to seek MAID who is currently in a penitentiary. Could you walk us through the steps and maybe comment on how many cases we have seen over the past five or six years since MAID has come into action?

**Dr. Adelina Iftene:** For the number of cases, the answer is that I don't know. When I filed through the Access to Information Act, I was told after one year that it's too private to answer. The lack of accountability and oversight is so significant that we cannot access any reliable information on this issue. That's how serious the matter is.

The Office of the Correctional Investigator reports three cases of MAID somewhere two years ago, but we don't know how many people asked.

The procedure itself basically says that the individual has to apply and is assessed by the prison physician, so it's not an independent assessor; it's somebody who works in the prison system. If the prison physician says that the person is eligible for MAID, then they would be seen by a second assessor, who should be somebody independent in the community. If the prison physician says they are not eligible, the assessment ends there, which, to my understanding, is quite different from what happens in the community.

That is briefly the process itself. If the individual receives MAID, again, the matter ends there. Normally, CSC has an obligation to conduct reviews of all the deaths that occurred in prison, natural or not natural, and obviously the causes that led there. They are exempted by legislation to do so in cases of MAID, which, of course, is a significant problem in terms of oversight and in terms of the lack of safeguards for how these assessments are done, what else is being made available and what the alternatives are. Right now, as it stands, it's particularly problematic, as I said, even leaving aside the discussion of lack of release mechanisms.

**Mr. Gary Anandasangaree:** Is the initial assessor qualified to provide MAID assessment?

**Dr. Adelina Iftene:** I don't know what qualifications they have. They are the prison physician, so whether every prison physician is otherwise qualified or not, I don't know. My guess is that they are not always qualified. It would be hard to believe that was the case.

The other issue, I would think, is independence. I think there is a problem when the prison physician is somebody who's working on contract for CSC.

[Translation]

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** Mr. Thériault, you have two minutes.

**Mr. Luc Thériault:** Dr. Lussier, we could pick up where we left off a little earlier.

Please tell us about pleasant dementia?

**Dr. David Lussier:** People are always somewhat reluctant to discuss pleasant dementia. What we call pleasant dementia is a condition that affects people who are happy in their everyday lives and

who exhibit no objectifiable suffering. They don't necessarily recognize their loved ones or have any idea of the day or date but are happy in the moment. For example, they are happy eating and taking part in small-scale activities. They appear entirely satisfied and happy.

Should we consider that these people are suffering enough to make an advance request? That's a big question.

Some people say they're happy now. However, if they had seen themselves in this condition before they fell ill, they might have decided they wouldn't want to live with that situation. Some feel that, if all they love doing is eating and taking part in small-scale activities at the long-term care centre, that's not a life worth living. It constitutes existential suffering for them and they prefer to receive medical assistance in dying. However, people may also adapt and become happy.

We talked about refusal earlier. It's all the more difficult to administer medical assistance in dying to someone who seems happy and absolutely doesn't remember requesting it several years earlier. That's the problem with pleasant dementia.

• (1925)

**Mr. Luc Thériault:** In that sense, unless the third-party says that an assessment would be necessary in accordance with the patient's wishes, the attending team can't simply trigger the assessment process because they consider it necessary. Consequently, the pleasant dementia issue should be included in the discussions involved in the multiple assessments process we discussed earlier.

**Dr. David Lussier:** Yes, I think it should also be involved in that when...

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** You have five seconds left. Go ahead.

**Dr. David Lussier:** When patients make their request, they could state that they wish to receive medical assistance in dying if they fall into a state of pleasant dementia.

**Mr. Luc Thériault:** All right, thank you.

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** I now give the floor to my colleague, Mr. Garneau.

**The Joint Chair (Hon. Marc Garneau):** We will now go to Mr. MacGregor, perhaps?

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** I had forgotten you, Mr. MacGregor.

[English]

**Mr. Alistair MacGregor:** Thank you, Madam Chair.

Dr. Lussier, I'd like to turn to you. You heard my previous intervention with Dr. Pageau, your colleague. I mentioned the testimony we had about how there can be clearly defined, objectively assessable criteria. That may be in response to his concerns about interpretation. I want to invite you to offer any comments on that.

Also, I know you've said that you would like advance requests to be available post-diagnosis, but do you have any opinion on how often that advance request should be renewed or reviewed so that we can be sure the patient's opinion is not changing as they progress?

[Translation]

**Dr. David Lussier:** In response to the first question, in keeping with what my colleague was saying earlier, yes, there can be objectifiable symptoms. If, according to someone, having both stool and urine incontinence is a form of suffering that is intolerable and objectifiable to that patient, who has in fact repeatedly experienced this incontinence, it can be a criterion that could be used to act upon the advance request.

As for the number of times the request should be reassessed, that really depends on each person and the stage they have reached. The process is designed simply to ensure that the wish has remained stable over time and that it factors in all the changes associated with dementia.

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** Thank you, Mr. MacGregor.

It's now time to give the chair to my colleague Mr. Garneau.

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

[English]

Colleagues, this brings our panel to a close.

I'd like to sincerely thank our witnesses today.

Ms. Iftene, thank you for shedding some light on the issue of MAID in the context of correctional services.

• (1930)

[Translation]

Dr. Lussier and Dr. Pageau, thank you for your presentations and your answers to our questions on this exceedingly complex subject of advance requests for medical assistance in dying. Thank you for having given us your time this evening.

We will now pause for a few minutes to prepare for the next group of witnesses.

• (1930) \_\_\_\_\_ (Pause) \_\_\_\_\_

• (1935)

[English]

**The Joint Chair (Hon. Marc Garneau):** We will start the second panel. I note that we're starting seven minutes late, so we'll carry on until 8:37 to have the full hour.

I'd like to make a few administrative comments before we get going.

To the witnesses, before speaking, please wait until I recognize you by name, or my co-chair does. I remind everyone that all comments should be addressed through the chair.

When speaking, please speak slowly and clearly. We have translation and it's a challenging task to translate, especially when people speak too quickly. Interpretation in this video conference will work as it does in an in-person committee meeting. You have the choice, at the bottom of your screen, of floor, English or French. When you're not speaking, please mute your microphone.

With that, I would like to welcome our witnesses for panel two, who are here to discuss advance requests.

We have with us this evening Dr. Blair Bigham, doctor, emergency and critical care medicine at McMaster University, by video conference. We have Dr. Dorothy Pringle, professor emeritus at the Lawrence S. Bloomberg faculty of nursing at the University of Toronto, also by video conference. We hope our third panellist this evening, Sandra Demontigny, will join us in the next few minutes.

We will get going at this point. Thank you for joining us. The way we do this is that each of the witnesses will have a five-minute opening statement, and then we'll move on with the questions.

Dr. Bigham, if you're ready, please go ahead. You have five minutes.

**Dr. Blair Bigham (Doctor, Emergency and Critical Care Medicine, McMaster University, As an Individual):** Good evening.

It's a privilege to speak to you today in my capacity as an emergency and ICU doctor, as a scientist, and as an author of a book on how shifts in technology and society have changed our relationship with death.

Please accept my apologies for attending this meeting while on call in an intensive care unit north of Ottawa. I was invited to appear before this committee after I had committed to serving patients this evening during the Ontario health human resource crisis. Should I have to step away for a medical emergency, I hope it is only briefly.

In my 17 years as a paramedic and doctor, I have seen many people die, but the people I see die are usually different from those we think of when we talk about palliative care or MAID. Emergency department and ICU patients sometimes die slowly from chronic disease like cancer or congestive heart failure. Other deaths come quite suddenly and unexpectedly after a car crash, a severe infection or a ruptured aneurysm.

Many of my patients hope to recover fully and live a long life. To accomplish that, teams of doctors, nurses, respiratory therapists and other professional lifesavers jump into action using medicines and machines, scalpels and science to avert death and pull people back from the cliff's edge. But at the time we initiate resuscitation, the outcome is far from certain. Sometimes no amount of drugs or devices can save a life. Sometimes I cannot make you better.

A modern dilemma has emerged with advances in medicine, which has led to a crisis in dying. For some patients, after a while it become clear that the machines keeping them alive cannot help them recover but are preventing them from dying. Tethered to machines that have failed to restore their health, they exist in a lineal space between alive and dead. Many of us would not want to exist in this way.

Individual values and predetermined wishes are already used by hospital teams to place limits on medical interventions, set goals for care, and alleviate pain and suffering. The rub comes in that the well-intentioned application of technology to save a life often fails to do so but prevents patients from crossing the finish line to die with dignity and peace.

Some might argue that pragmatic similarities between MAID and our current practice of withdrawing life-sustaining technology exist. For some, withdrawal of technology results in nearly immediate death, and comfort is maintained with various medications. But for others, withdrawal of technology results in a lingering that is undignified and sometimes distressing. Even when technology is removed, death, though certain to come, can be slow to arrive.

It's my opinion that Canadians deserve to have a say in their own ending, because now, for the first time in human history, technology can and does prevent nature from taking its course. There is likely a larger role for MAID to play in acute-care settings where consciousness and the ability to consent are often compromised.

Adjacent to the question of MAID is the broader one of how we can better inform Canadians of their choices during unrecoverable critical illness and engage their loved ones in discussions around end-of-life values before tragedy strikes. The challenge that I believe this committee must consider is one that all Canadians must contemplate. Prognostication is often uncertain and always complex. Knowing when the likelihood of a successful recovery falls short of the medical team's capabilities and a patient's own wishes is fraught with difficulty.

I hope today I can assist your deliberations around how advance directives regarding medical assistance in dying can contribute to alleviating this modern-day death dilemma so that no Canadian dies too soon or too late.

Thank you.

• (1940)

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

We'll now go to Dr. Dorothy Pringle for five minutes.

**Dr. Dorothy Pringle (Professor Emeritus, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, As an Individual):** Thank you.

I'm a retired registered nurse with a background in psychiatric and gerontological nursing. I've practised and have taught nursing students in both acute care and long-term care facilities.

I had the pleasure and the opportunity to be a member of the Council of Canadian Academies expert panel on medical assistance in dying and on MAID and advance requests.

I'm strongly supportive of MAID and advance requests for MAID. I think that patients with devastating terminal illnesses that do not affect their cognition—for example, most types of cancer, cardiac conditions and amyotrophic lateral sclerosis—gain a sense of control and comfort by determining when and under what conditions they will be relieved of pain and suffering.

More challenging are diseases that result in dementia and the loss of cognition, which require someone other than the patient to take responsibility for initiating MAID based on conditions specified by the patients. The Netherlands experience indicates that MAID following a patient's loss of competence is rare but difficult. Most patients with dementia exercise the MAID option while they are still competent.

Now, practices to enhance the effectiveness of advance requests have been identified, but we have little understanding of how effective they are. I think a critical issue is the management of advance requests when the patient is cognitively impaired. We have some advantages to bring to this. We have lessons from the Netherlands, which has excellent oversight and very good data, and we have experience with MAID across Canada on which we can draw.

Thank you.

• (1945)

**The Joint Chair (Hon. Marc Garneau):** Thank you very much, Dr. Pringle.

I believe I see Ms. Demontigny with us.

[*Translation*]

Ms. Demontigny, you have five minutes for your opening address, to be followed by some questions.

**Mrs. Sandra Demontigny (As an Individual):** Thank you, Mr. Chair.

Contrary to my usual approach before I became ill, I'm going to read what I've written here because otherwise I'll never manage.

It's with a feeling of urgency in body and soul that I submit this brief to the House of Commons Special Joint Committee on Medical Assistance in Dying.

I'm going to begin by reading you an excerpt from the report of the Groupe d'experts sur la question de l'inaptitude et l'aide médicale à mourir, prepared on behalf of the Government of Quebec.

Sandra Demontigny was only 39 years old when she was diagnosed with Alzheimer's disease. Her father died of it when he was 53, after having suffered symptoms that had a significant impact on his dignity. Ms. Demontigny has the rarer hereditary form of this serious disease.

This young woman has a family, a spouse and three children. Her youngest is 16 years old and her eldest 24. Her children also have a 50% risk of being struck by this hereditary form of Alzheimer's disease.

...because of her concern for the fate of people who, like her, are affected by a neurocognitive disorder, and what it means for the friends and family who support them every day, Sandra Demontigny gets involved in research projects on the disease and speaks publicly in order to provide clarification. She grants interviews to make elected representatives and the general public more aware of the issue of extending MAID to people affected by a disease that will eventually make them unable to consent to it.

Here we are a few years later. I'm now 43 years old and submitting this brief to the House of Commons. I am doing this in order to share my life experience with early-onset genetic Alzheimer's disease, as a caregiver and as someone who now has the disease. I will also tell you about what the years to come are going to be like as, gradually but steadily, my grief and my fears worsen. I know precisely what to expect. I've seen it close up over the years with my father.

Since learning of my diagnosis in 2018, I've been focusing my energies on preparing my departure to make it as gentle as possible. It's better to look for the positive side. I am working to calm my vanishing brain and my troubled heart. I feel a need to be reassured about my future so that I can do a better job of living out my remaining days and coping with the more frequent trials I will be experiencing.

My plan is to make the most of my final years while life is still good, with a free mind and without fear. Together with my mother and my brother, I cared for my father, Denys, until the end of his illness. He died at the age of 53. He had the same genetic defect as his mother, his mother's mother, and so on.

The risk of genetic transmission is 50%, so it's heads or tails. If that genetic mutation happens to be there, the disease will develop in 100% of cases. This genetic version is early-onset, when people are in their 30s or 40s, depending on the gene responsible. This is usually the mother or father of relatively young children who will in some form or another become caregivers. My three children are my caregivers every day. It's important to point out that each of them has a 50% risk of having the same disease as the affected parent. It's a spectre that weighs very heavily on adolescents and young adults.

I'm categorical about this. Since caring for my father as he descended into the hellfire of Alzheimer's disease, I know that I do not want to go through what my father did. It's out of the question. I don't want to end my life having completely lost all my dignity. I don't want to crawl around day and night because I'm too tired and frequently crying, evasive or lost, managing a few words that are difficult to understand, and becoming aggressive with the children I

don't even recognize anymore. I'm forgetting more and more, but I'm still living with my memories of my father, 15 years later. I'm convinced that they will disappear once I have been able to calm them by telling them that they don't have to live again in me.

Our Canadian policy is progressive and humane. Canadians are demanding the legalization of advance requests for medical assistance in dying, MAID, particularly following an Alzheimer's disease diagnosis, in order to be able to live their remaining years more comfortably in body and mind, and to fully and serenely savour each of their remaining days, knowing that when the time they have specified in their advance request arrives, they will be able to rely on their proxy to exercise their right to die in dignity.

Thank you, senators, for your interest in my presentation and my brief. It was an honour to share my life experiences with you and to give you my opinion about advance requests for medical assistance in dying.

● (1950)

**The Joint Chair (Hon. Marc Garneau):** Thank you very much, Ms. Demontigny.

We will now go to the questions.

I'm giving the chair to Senator Mégie now.

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** Over to you, Mr. Ellis.

[English]

**Mr. Stephen Ellis:** Thank you very much, Senator.

Thank you to the witnesses for being here on this very important topic for all Canadians.

That was a very passionate speech, Madame Demontigny. It's a difficult topic and there are difficult questions. However, I think they're important. Again, it's very personal. If you're uncomfortable, I understand that.

How do you choose a time when your suffering has become too much? How do you come to that decision, assuming you still have the ability to make that decision?

Have you given that some thought and discussed it with your health care provider?

[Translation]

**Mrs. Sandra Demontigny:** Yes, I still ask myself what moment I should choose.

I am leaning more and more towards when I have trouble recognizing one of my relatives, especially one of my children. I know that it's going to happen, and for me, that's the last straw. You have to have a cut-off point somewhere, but it's not easy.

That's my opinion right now, but to be honest, I have to admit that I haven't yet made up my mind.

[English]

**Mr. Stephen Ellis:** Thank you very much for that. I appreciate it.

Of course, the difficulty then becomes that sometimes in dementia, we have fluctuations in our ability to recognize people. Have you given that some thought, as well? You may have a good day and you may have a bad day. Is it a combination of those things?

Again, I apologize for asking these questions, but I think it's important that we understand this from someone like you. Thank you, again, for being here.

[*Translation*]

**Mrs. Sandra Demontigny:** That's very kind. Don't be shy. Those are very good questions.

You're right to say that there are good days and bad days when you have Alzheimer's disease.

I want to cling to my basic values and to the things I don't want to go through. I don't want to lose my dignity and have to depend on everyone for my basic needs, by which I mean to eat, change my diaper and put me to bed, because I can no longer tell the difference between daytime, evening and night. Those are a few guideposts.

There is of course the risk of leaving too early, but although I love life, I'd rather leave a little bit early than a little bit late, when I can no longer make the decision and would be unable to give my consent.

[*English*]

**Mr. Stephen Ellis:** Once again, I appreciate the answers.

I have another question to ask, if I might. We've heard from other witnesses that life may change. I understand you have a child who is 20. Again, I apologize for asking this, but I think it's important that I understand. If your child of 20 were to have a child, who would be your grandchild, do you think that might have any impact on your decision-making?

• (1955)

[*Translation*]

**Mrs. Sandra Demontigny:** That's a very good question.

At 43 years old, I've been a grandmother for a year already. Life has been good in some ways. I'm spoiled because I already have my first grandson and I'm happy that he's there.

I'm facing a difficult situation, because I have to decide up to what point I want to experience the good times, when I know that there is a risk of some truly bad times. One fine day, in my view, these moments will be stripped of any dignity. Unfortunately, I won't run that risk.

I will really have some difficult choices to make, but I don't want to risk being imprisoned in my body for years. I don't want to make mistakes or get aggressive. So much so that, unfortunately, I will probably go a little earlier than I would ideally have liked to.

[*English*]

**Mr. Stephen Ellis:** I have a final question, through you, Chair.

Has your family expressed any discomfort with your decision and that they want you to be around longer than you might choose to be?

[*Translation*]

**Mrs. Sandra Demontigny:** No, the members of my family are all in full agreement.

**Mr. Stephen Ellis:** Thank you very much.

**Mrs. Sandra Demontigny:** Thank you.

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** Over to you, Mr. Arseneault.

**Mr. René Arseneault:** Thank you, Madam Chair.

Thank you, witnesses.

Ms. Demontigny, it's so very important for us to hear from you today because you bring a different perspective on advance requests. I want to express my immense thanks. We've heard other witnesses who have made such a request, but you are still youthful, which is cruel, as you've explained, because one day you're going to have to choose to leave too early rather than too late.

We've heard a number of witnesses say that people who were against advance requests for medical assistance in dying were demonstrating ageism. How do you feel about that?

Do you think that you're going to be overprotected by people who say that you're too young to be aware of what you're asking for and that you didn't know exactly what it was that you want? What can you tell us about that?

**Mrs. Sandra Demontigny:** Thank you for that question. It's an interesting one.

Advance requests for medical assistance in dying are interesting precisely because one can still think and make decisions. At the moment, although I have Alzheimer's disease at a moderate stage, I can still speak to you relatively well.

I'd rather be able to decide when I've reached my limit, or at least the one I think I've reached, at the risk of getting it wrong, then allowing too much time to go by and reach a stage at which I can no longer express myself clearly.

What I'm about to say may be stupid, but I know that the end of my time with Alzheimer's disease might be very difficult, both physically and mentally. But what I don't want to do is allow my destiny to be in the hands of someone who would let me remain ill like that for a long time.

My father got to the end of his disease relatively quickly. The difficult years did not last very long. But my grandmother, meaning his mother, was in a neurovegetative state for seven years.

**Mr. René Arseneault:** I know what that's like. There were several cases on my father's side of the family.

**Mrs. Sandra Demontigny:** So you know what I'm talking about.

**Mr. René Arseneault:** Yes, very well.

If advance requests were allowed today, would that make you feel better, given that you've been diagnosed with Alzheimer's disease? Would you make the request right now?

How might it change your life?



**Mrs. Sandra Demontigny:** You're right. It would be an immense relief, for me and for my family too, because they know it's important to me. It would enable me to decide on the right time to leave. I'd prefer to go at the age of 80, of course, but I know that won't happen.

The one thing I'm afraid of is letting things go on for too long and get to the phase at which I can no longer give my consent. I'm afraid of being a prisoner in my body and having to do miserable things to myself to try and put an end to my life, which is something I don't want to do.

• (2000)

**Mr. René Arseneault:** Thank you very much for your testimony, Ms. Demontigny.

[*English*]

Ms. Pringle, in the context of your work as a nurse, what are your thoughts on what you've just heard from Madame Demontigny?

**Dr. Dorothy Pringle:** I think her testimony is about all we need to know about how important it is to have advance requests. I think she presents the biggest dilemma in the whole area of advance requests, and that is for people with dementia where they are in favour of MAID.

Again, if they choose while they're competent to take advantage of MAID, I don't think there's an issue. That is the experience in the Netherlands, which has a lot of experience with this. Very few of the patients there who are cognitively impaired in fact go on to the point where they cannot make the decision and they rely on others. Most of the folks who are cognitively impaired make that decision before they are no longer competent.

I think in the legislation we need to think through whether or not we will continue to permit advance requests after the person is cognitively impaired.

[*Translation*]

**Mr. René Arseneault:** Thanks very much to all the witnesses.

[*English*]

That's all the time I have.

[*Translation*]

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** I am now going to give the floor to Mr. Luc Thériault for five minutes.

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

Ms. Demontigny, you concluded your testimony by saying that it was an honour for you to meet members of Parliament and senators. I'd like to tell you that this honour is reciprocal. It's not in fact the first time I've heard you, but it's the first time that I've been so deeply affected and overwhelmed. Perhaps it's because of closer proximity.

You used some very powerful words, including, "my vanishing brain and my troubled heart", and said that you didn't want to be imprisoned in your body.

I'm trying to determine what would be the best conditions for someone suffering from a major degenerative neurocognitive illness to be able to live as long as possible, with the assurance of knowing that their wishes would be complied with, even when they are no longer able to state their point of view, and that everything possible will have been done to allow a proxy, together with the care team, to trigger the process, even if the care team says they do not think the time has yet arrived and that there is no hurry.

What I find staggering this evening is your telling us that you wouldn't wait until you were unable to make this decision, and that you would rather shorten your life. As a legislator, I'd like to be competent enough to prevent you from having to do that.

Why, at the moment, do you believe you would have to do it before becoming incapable of making decisions?

**Mrs. Sandra Demontigny:** It's because I can't make an advance request for medical assistance in dying. That's the key.

**Mr. Luc Thériault:** But if it were allowed, it could change your point of view.

**Mrs. Sandra Demontigny:** It would certainly allow me to live with my disease for a longer period. Right now, however, advance requests for MAID are not available. So there definitely would come a time when I wouldn't want to take the risk that things worsen too much and that I would want to move quickly before I lose my ability to make informed decisions. But with an advance request, I would be able to clearly establish what is acceptable for me and what is not. Moreover, I've already spoken with people close to me, my children, and everyone is in agreement.

Ideally, however, I would like to live for a relatively long time. I want to experience part of my illness. I don't want to leave at the beginning, and I'm willing to accept being lost and needing assistance.

However, I don't want to experience the final phase of the disease, completely dependent and unable to express myself very much, if at all. I've seen it and I don't want to live through it. That's what I would specify in an advance request. It would definitely give me more time.

Without wishing to put pressure on you, if advance requests were not approved by Parliament, then unfortunately, I would have to decide to leave before entering that phase, in order to avoid becoming trapped.

**Mr. Luc Thériault:** I heard that, and it's why I'm so deeply moved.

I think we can get there because it seems to me that for decisions as personal as having to freely decide on one's own death, I can't see why the state should get involved, particularly given the conditions you've experienced. You and your children are very much aware of what to expect. In fact your testimony talked about a family process.

Some people see wrong everywhere, and people who might take advantage of the situation. What I would denounce is a paranoid legality-ridden process surrounding a decision that is perfectly serene, that involves individuals affirming the fact that they are human beings, that they have the right to decide, with freedom of conscience, when they are going to leave this world and would like someone to help them do so.

I, for one, am prepared to help you.

• (2005)

**Mrs. Sandra Demontigny:** Thank you, Mr. Thériault. I am happy to hear that.

You're right when you say that it has become a family process. From the moment I mentioned the advance request option to my children, they felt that it was very sensible. It's clear to them that having poor quality of life and being bedridden for three, four, five or even 10 years, makes no sense. I don't want that, and neither do they.

Their risk of having this disease is 50%. They told me that they would make the same decision as I have if they were to receive that diagnosis.

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** Mr. MacGregor, you have five minutes.

[*English*]

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

Thank you to all of our witnesses.

Madame Demontigny, thank you.

In all of our conversations around this committee, when we've been speaking about dementia, most of the testimony has been from professors and from people in the medical profession who can speak about the disease generally and of specific cases in a slightly abstract way. I think your testimony is very powerful because you're here as someone living with dementia. You know what's coming your way and you are pleading for autonomy over your own life. I think that's a very powerful statement.

I want to ask you a question about the stigma that is associated with dementia. We have heard several witnesses talk about how, when people first receive a diagnosis of dementia, they may not be familiar with the disease intimately, but they do know generally that it's a disease that goes down a very negative path, which might influence their decisions.

You, however, have a very intimate knowledge of the disease because of your family history. In your opening remarks, you talked about how you wanted to avoid the descent into hell that your father went through. You understand this disease very well.

Can you maybe talk about your own personal experience with the stigma associated with the disease as a person who's intimately familiar with it? I think you offer some good insight into that.

[*Translation*]

**Mrs. Sandra Demontigny:** Thank you.

You have said a lot of interesting things and I feel that they are a little mixed up in my mind.

You're right in saying that I know the disease from the inside.

To be honest, I wouldn't want anyone to have to care for a young person with Alzheimer's disease. Older people often die before getting to the end of the disease, the stage at which the symptoms are horrendous. Younger people don't die because they are in good shape. My father had been very athletic and wasn't dying.

I would have trouble believing that anyone who has witnessed this kind of end-of-life process and was afterwards diagnosed with Alzheimer's disease would choose to carry on to the very end. It's clear that I certainly wouldn't.

My father was well cared for. There were people there for him. Nevertheless you could see the suffering on his face and in his eyes. His face looked tense. He cried when he would look at me but was unable to speak any more. He crawled around on the floor. He licked the floor. I don't think that most human beings would want to do that. I don't want to go through it. Knowing what it is, I want to avoid it.

Other people have a different view of the end of life and that's fine. The ideal is to allow everyone to follow the path that suits them, on the basis of what life gives to them.

Life gave me a poisoned chalice. I decided to be proactive and work towards living a dignified life in spite of Alzheimer's disease. That's not really possible right now.

• (2010)

[*English*]

**Mr. Alistair MacGregor:** Thank you for that.

We've also had some witnesses who have been concerned that if advance requests were permitted, there might be some difficulty interpreting the wishes.

Do you have any concerns that if we allowed advance requests...? I think you are of the opinion that you would be able to clearly articulate the conditions of the disease for which you want medical assistance in dying to be triggered. Can you offer any personal thoughts on those concerns that we heard earlier?

[*Translation*]

**Mrs. Sandra Demontigny:** That's very interesting.

I won't hide from you the fact that it's an area I know well. I worked in the health field and cared for my father throughout his illness. So I'm familiar with the subject. That's not necessarily the case for most people and it can be complex.

In the health system, some people, like social workers, support people as they deal with a number of procedures. They also help them fill in complex forms. There are also psychologists who can help the people who are ill to understand things when required. These are very helpful people.

I have access to a psychologist and a social worker. I speak freely with them about my experience with Alzheimer's and the process I'm going through. It does me a lot of good. If they can't answer my questions, they will, when required, go and obtain information for me and tell me about what they found. It's important for people to have access to these services, which are difficult to obtain in the health system. However, to make a well-informed decision after having examined the entire range of possibilities, what's required, in my opinion, is access to qualified professionals.

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** I am giving the chair back to Mr. Garneau.

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

We are now moving on to questions from the senators.

I see Senator Dalphond, and thus presume that Senator Kutcher is not with us.

We will therefore begin with Senator Dalphond, who has the floor for three minutes.

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

I'd like to thank Dr. Bigham, Ms. Pringle and Ms. Demontigny for being here with us this evening. Your testimony is extremely important.

My question is for you, Ms. Demontigny. It's a difficult one. Certain people have said that when someone has Alzheimer's disease, the self changes and a state of contented dementia can be achieved. Have you ever experienced this personally? Do you agree with it? Would you say that contented dementia is a stage that has to be gone through before receiving medical assistance in dying? Do you think the final stage comes when the patient suffers from aspiration pneumonia, dual incontinence, and other things like that?

• (2015)

**Mrs. Sandra Demontigny:** That's an excellent question and I'm glad you asked me.

There are indeed some professionals who often speak about contented dementia. To be quite honest, I don't believe in it. Contented dementia amounts to symptoms of a disease being expressed. It's not that the person is content, but rather that brain plaques have disrupted their neurotransmitters, causing what appears to be expressions of joy. No one has ever told us that they feel happy, even though they appear to be. I honestly find it sad to hear people say this, and I've often heard some health professionals who practise medical assistance in dying say that when people experience contented dementia, they are happy. We just don't know.

I can tell you today what behaviours would make me feel that I'm losing my dignity, for example, if I no longer recognized my children, if I couldn't manage to go to the bathroom alone or if I couldn't eat by myself. These are behaviours that I've mentioned already and that are readily observable.

Some people won't like what I'm going to say, but I think that contented dementia is just a concept that some caregivers are fond of. They want to believe that the patients are happy. But we don't

know if they are and we can't assume that they are, hence the interest in advance requests.

**Hon. Pierre Dalphond:** Contented dementia is not a state you would like to experience, but you could acknowledge that someone else might be ready to experience it and wait until a later stage to obtain medical assistance in dying.

**Mrs. Sandra Demontigny:** Absolutely. The decision about the stage of the symptoms at which action is required might differ from one person to another, and that's fine.

**Hon. Pierre Dalphond:** Thank you.

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

[*English*]

We'll now go to Senator Wallin for three minutes.

**Hon. Pamela Wallin:** Thank you very much.

I have a brief question for Sandra.

Again, thank you for your comments here tonight.

I just want to ask whether you have created a list of symptoms that would be unacceptable to you. Have you discussed that with family and caregivers, and are they in agreement?

[*Translation*]

**Mrs. Sandra Demontigny:** The answer to all these questions is yes.

In my case, it will be when my autonomy for my basic needs will have been significantly altered. It will be when I can no longer eat or go to the bathroom on my own, or be unable to wash myself. For me, it's autonomy. I may be too proud, but I don't want to share those things, particularly when I know that I have a degenerative disease that's not going to go away.

If I had an illness that meant receiving intimate care on a temporary basis, I think I could accept that, knowing that I would get better at some point. But I know that for me, things are going to get worse, and I have no interest in accepting such things. My children all agree—

[*English*]

**Hon. Pamela Wallin:** I'm going to—

I'm sorry. Go ahead.

[*Translation*]

**Mrs. Sandra Demontigny:** My children are all in agreement. They told me that if they were to experience the same thing, they would reach the same decision.

[*English*]

**Hon. Pamela Wallin:** I would like to hear from Dr. Bigham and Dr. Pringle on this.

We're living in a world right now without advance requests. To both of you as medical professionals, is Sandra's approach acceptable to you? She has a long record of saying these are her views; she has experience; she is prepared to write it down; and the family or substitute decision-makers have agreed. Is that acceptable in any way now, or would it absolutely require an advance request in order for her wishes to be met on receiving MAID?

● (2020)

**The Joint Chair (Hon. Marc Garneau):** We'll start with Dr. Bigham.

You'll each have about 25 seconds.

**Dr. Blair Bigham:** Specifically to the point on dementia, my current understanding is that it would be unacceptable to provide MAID without a clear duration of life expected. For that reason, advance requests would be required.

Advance requests may not be perfect, but we frequently see patients.... Ms. Demontigny said that she would rather die too early than too late. We see this in our technology-enabled world, where people forgo medical technology that could save their lives. They are afraid of rolling the dice and ending up in a worse situation where they are dependent on others to survive and where they're unable to communicate or contribute to society. For that reason, advance directives are useful far beyond dementia, cognitive decline, and other areas of chronic illness and perhaps acute illness as well.

**Hon. Pamela Wallin:** Let's have a quick word from Dr. Pringle.

**The Joint Chair (Hon. Marc Garneau):** Go ahead, Dr. Pringle. We'd like to hear your view.

**Dr. Dorothy Pringle:** At this point in time, from what Ms. Demontigny has told us, she would not be able to get MAID.

I think the only issue that we haven't talked about is that, when you are cognitively impaired and you have this list of indications of when you want MAID, somebody else has to initiate it. It has to be a family member, but if a family member isn't available, then it's probably going to go to the medical team. The difficulty that's been experienced is with somebody who doesn't know that patient well initiating MAID. It's a problem if there's resistance on the part of the patient because they're cognitively impaired and do not understand what's going on.

I think in the case of Ms. Demontigny, it's a perfect situation and a terrible circumstance in the sense of having family who are on board and who would be prepared to follow her directions. When that occurs, I think that's the intention of advance directives.

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

[*Translation*]

Madam Chair, you have the floor.

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** Thank you, Mr. Chair.

My question is for Dr. Bigham.

I know that you work a lot in intensive care. That's not the kind of place where you would find numerous people with dementia making advance requests for medical assistance in dying. But

among your intensive care patients, there are many for whom you will be disconnecting technological devices. Some will die, but others will live longer.

Based on your experience with these people, have there been any who have told you that they would have wanted to die when the tracheotomy tube was removed, or who asked whether they might one day be able to request medical assistance in dying?

Have you ever had this kind of discussion with a patient for whom you withdrew technological devices?

[*English*]

**Dr. Blair Bigham:** First of all, it's very unlikely that at that stage in someone's illness they're able to communicate with me, but I very often hear from family members along the lines of "Can we speed this up? It's torture for us watching this go on and drag out."

For many patients, when we withdraw technology, they die quite quickly. For others, they can linger for hours, for days, sometimes for weeks, but the outcome is certain. This can be very distressing for families, and occasionally it can be uncomfortable for patients.

For patients who require technology to have a shot at life, but for whom that technology then fails, there is certainly a role for assisted dying.

[*Translation*]

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** Thank you.

Ms. Demontigny, before asking my question, I'd like to thank you sincerely for having testified and spoken about your personal experience.

At some of the many lectures that you give, you must have encountered some families with approximately the same experience as you. What kinds of things do they say to you? For example, do they say that they would have wanted their mother to have requested medical assistance in dying? Or is it the other way around, and that they would not have wanted that so they could have more time to spend with them?

I've heard comments like that. But what have you heard when you meet people?

● (2025)

**Mrs. Sandra Demontigny:** Thank you for your question.

Of course, given my approach to end-of-life care, including care during the final phase of Alzheimer's disease, and as the spokesperson for the Association québécoise pour le droit de mourir dans la dignité, the people I meet are often those who have already given the matter some thought, who want to die in dignity and who hope that their expectations will be met.

I can talk to you about them.

As it happens, we had our annual meeting today. Quite a few people came to see me; they touched my arm and tears were flowing. They thanked me and said that's what their mother had wanted, but it had not been possible. Others thanked me by saying that they found it reassuring and they were encouraged, because they had been diagnosed as having Alzheimer's disease.

Of course those who were against the idea were not there, because it's an association for people who want to die with dignity. The comments I received were positive. People see it as the beginning of some form of relief and they were hoping for legislation that would help them achieve that. It gives them hope that they will end their life with dignity, which is not what their loved ones had experienced.

**The Joint Vice-Chair (Hon. Marie-Françoise Mégie):** Thank you very much, Ms. Demontigny.

[*English*]

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

This brings our panel to a close. I'd like to thank Dr. Blair Bigham and Dr. Dorothy Pringle for being with us this evening, providing their opening statements and also sharing their expertise with us.

[*Translation*]

Ms. Demontigny, we give you our sincere thanks.

As many of my colleagues have mentioned, your testimony was very powerful and moving. It was also extremely eloquent. You have obviously given a great deal of thought to the questions we asked you this evening, and your replies will be extremely useful to us in our deliberations.

[*English*]

Thank you again to our three witnesses.

This will bring our panel to a close.

The meeting is adjourned.

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