HOUSE OF COMMONS
CHAMBRE DES COMMUNES
CANADA

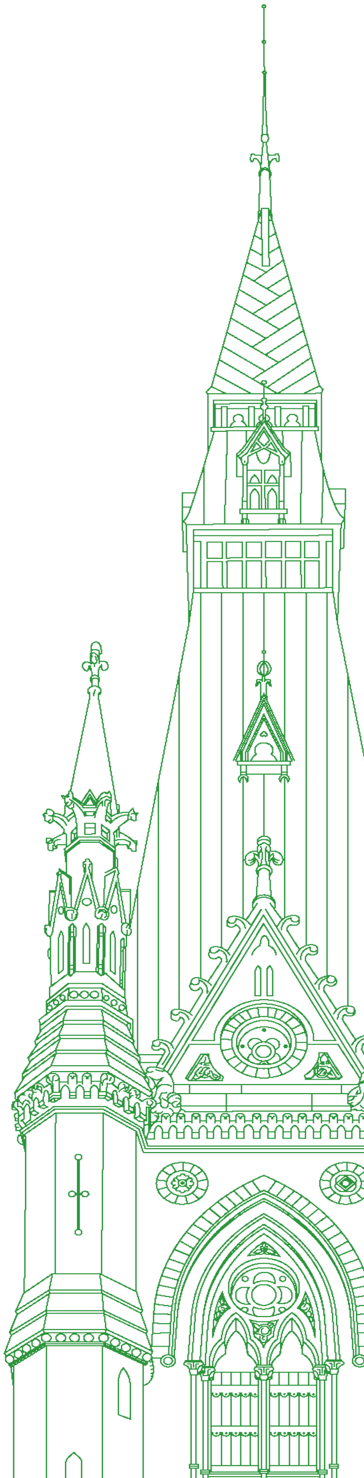
44th PARLIAMENT, 1st SESSION

Special Joint Committee on Medical Assistance in Dying

EVIDENCE

NUMBER 003

Monday, April 25, 2022



Co-Chairs:
The Honourable Marc GarneauThe Honourable Yonah Martin

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● (1915)

[*English*]

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

Good evening, everyone. Welcome to this meeting of the Special Joint Committee on Medical Assistance in Dying.

I'd like to begin by welcoming members of the committee, witnesses, as well as those watching this meeting on the web.

My name is Marc Garneau, and I am the House of Commons joint chair of this committee. I am joined by the Honourable Yonah Martin, the Senate's joint chair.

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.

[*Translation*]

You are all familiar with the Board of Internal Economy directives concerning health protocols, so I am not obliged to repeat them. I hope you will all adhere to them.

I would also like to remind members and witnesses to keep their microphones muted, unless recognized by name by the joint chair. A reminder that all comments should be addressed through the joint chairs. When speaking, please speak slowly and clearly.

Interpretation in this videoconference will work like in an in-person committee meeting. You have the choice, at the bottom of your screen, of either Floor, English or French.

[*English*]

First, there's some very quick committee business.

On Wednesday, April 20, the subcommittee on agenda and procedure met to consider committee business and made some recommendations. Pursuant to House of Commons procedure, the committee must ratify the subcommittee recommendations to put them in force.

Those recommendations are as follows: One, hearings are divided into three one-hour panels; two, written briefs must be received by May 9 and not exceed 1,000 words; three, today's testimony is from practitioners and family members, and the next meeting's theme will be palliative care; and four, themes that we will be dealing with during this committee's meetings are in the following order: palliative care, advance directives, disabilities, mature minors, and mental health, in that order, as I said.

The clerks have distributed report one of the subcommittee on agenda and procedure. Do members have any changes they wish to propose to the report, or are they ready to endorse it?

Does anybody want to make a change?

I don't see anything, so is it the pleasure of the committee to adopt the report?

I see unanimity.

With that, I would like to welcome our witnesses for panel number one and turn it over to Senator Yonah Martin.

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

I'd like to introduce our witnesses. We have, appearing as an individual, Dr. Félix Pageau, geriatrician, ethicist and researcher, Université Laval. From the Canadian Association of MAiD Assessors and Providers, we have Dr. Stefanie Green, president, MAiD practitioner, adviser to the B.C. Ministry of Health. From the Canadian Nurses Association, we have Tim Guest, chief executive officer, and Barbara Pesut, principal research chair in palliative and end of life care, University of British Columbia, Okanagan.

I'd like to make a few comments for the benefit of our witnesses.

Before speaking, please wait until I recognize you by name. I remind you that all comments should be addressed through the joint chairs. When speaking, please speak slowly and clearly. Interpretation in this video conference will work like 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 are not speaking, please keep your microphone on mute.

With that, I'd like to welcome our witnesses for this panel. You each have five minutes. We'll begin.

● (1920)

[*Translation*]

Mr. Luc Thériault (Montcalm, BQ): I'm having a technical problem, Mr. Chair.

The sound in the room coming from people attending virtually is much too loud for me to be able to understand the interpretation in the room. Would it be possible to adjust the volumes?

Thank you.

[*English*]

The Joint Chair (Hon. Marc Garneau): Okay.

Madam Co-Chair, somebody has said that we need to make an adjustment to the volume of the voices for those in virtual attendance. If we could suspend for a minute, we'll try to adjust that.

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

The Joint Chair (Hon. Marc Garneau): We've made an adjustment.

Hopefully, Monsieur Thériault, it will be acceptable.

Please continue, Co-Chair.

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

We'll have our first presentation with Dr. Félix Pageau for five minutes, please.

[*Translation*]

Dr. Félix Pageau (Geriatrician, Ethicist and Researcher, Université Laval, As an Individual): Good evening. Thank you for giving me the opportunity to make this presentation.

I am going to read the main points in my brief.

Some Canadian and Quebec organizations are suggesting that medical assistance in dying for people with major neurocognitive impairments could relieve their suffering. It is also assumed that dementia can be seen as horrible defect, and that this is how a majority of Canadians and Quebeckers would see it. People who are afraid of suffering cognitive impairments will go so far as to wish for their own death. In this short brief, we will show the reasons why it is not ethical to permit the administration of medical assistance in dying, or MAID, for people suffering from dementia, by way of advance medical directives, or AMD.

My argument is threefold: it is practical, it is emotional, and it is supported by the principle of autonomy, put in context.

I will address the practical side first. In terms of health care in Canada, there is a serious shortage of geriatricians. Although some family doctors assess dementias and their consequences, it seems that an expert eye is needed for determining the level of suffering experienced by a person with advanced dementia. It is very difficult to predict the evolution of a cognitive illness with certainty. There are few reliable criteria for assessing pain, mood disorders and existential suffering. Often, when there is no reliable tool in a clinic, an expert opinion is sought. In the case of advanced dementia, there are few experts in the field: geriatricians, geriatric psychiatrists and physicians who work in LTCHs or nursing homes. There are very few of these specialists in Canada.

As well, in the Netherlands, the only country that allows euthanasia by advance request, a majority of those expert physicians do not follow advance medical directives, because the directives are often not clear or are even inconsistent with the reality of care. In practice, therefore, MAID by AMD is not applicable in Canada because of the shortage of specialists who are able to assess people with dementia who will want access to MAID. As well, when access to euthanasia by advance medical directives is allowed, as in the Netherlands, the directives are only very rarely applicable.

In addition, in Quebec, a group of researchers has pointed out that the Quebeckers participating in their study did not really understand what MAID and advance medical directives are. That is not the strongest ethical argument, since the number of geriatricians, geriatric psychiatrists and physicians in long-term care homes could be increased. It would obviously be a major challenge, but it is not impossible in absolute terms. With more research in gerontology, we could establish reliable scales for assessing physical, psychological and existential suffering for patients with advanced dementia. This research still has to be adequately funded.

Finally, if patients were guided by their physician to fill out their AMD, they could write directives that are meaningful in terms of their clinical situation, or nearly so. It is therefore important to analyze other emotional and ethical arguments against MAID for patients with dementia.

I will now talk about the fear of decline. Dementia causes losses of functional autonomy. That means that it causes difficulties in performing household and day-to-day tasks. Of course, we understand that people are afraid of dementia because of the mass deaths in LTCHs and nursing homes because of the COVID-19 pandemic. But that fear is only partially justified. There has been a lack of care and we still need to improve geriatric services. We can train and hire more caregivers in Canada. As well, valuing the work done by family caregivers and adding resources of every nature will be essential.

Apart from the strong desire to improve geriatric care in Canada, other actions are needed in order to reduce the fear of “decline” associated with cognitive losses. We also have to combat the prevailing ageism. That term refers to discrimination against older people through malevolent attitudes, disrespectful behaviour and hurtful words. The medical profession and the prevailing culture are imbued with ageism in the West, and this leads to poor practices. In our opinion, one of them is MAID for patients with advanced dementia. Often, a senior who is in a situation of vulnerability because of cognitive impairment is not considered to be a full member of society because they are not working and are not profitable to society. That is the economic liberal view of human beings, which defines the value of an individual by their capacity to work, and it is wrong. It leads to discrimination and even hatred of persons with dementia. Decline is assumed, because the individual has disabilities, a mental illness, and cognitive impairments associated with dementia. As Canadians, we will have to stand up for vulnerable seniors.

In my professional experience, we sometimes even have to persuade seniors that they still have value in spite of their cognitive deficit or psychiatric illness. Seniors can internalize that hatred of themselves. What I mean by “internalize” is a well-known concept for other forms of discrimination. A person who frequently hears disrespectful remarks aimed at themself will ultimately believe that their supposed defects or problems are real. The same is true for ageism. Even though the person should defend themself, they come to accept and even believe the negative prejudice aimed at them, and to request MAID. However, we have to recognize their individual value, which is not limited to their age, their productivity or the fact that they have no disability.

● (1925)

The human individual has intrinsic value: that is the dignity, the real dignity, the dignity that we can never lose, as the philosopher Immanuel Kant meant it.

[*English*]

The Joint Chair (Hon. Yonah Martin): Thank you. We have a time limit of five minutes, and you went a bit over, so I'll try to give a 30-second warning to our next speakers.

We now have Dr. Stefanie Green.

Dr. Stefanie Green (President, MAID Practitioner, Advisor to BC Ministry of Health, Canadian Association of MAiD Assessors and Providers): Thank you to the committee for the opportunity to speak with you today.

I'm here as the president of the Canadian Association of MAiD Assessors and Providers, the clinical subject matter experts on MAID in Canada, and as an experienced practitioner.

As my remarks must be limited, I will not dwell on the elements of implementation that have proven both important and well done. Rather, these are fleshed out in my written brief, but I will highlight the most important and I am willing to discuss further if you wish.

The fact that we allow clinician-administered MAID, that MAID is not restricted to terminal illness or imminent death, and that we simultaneously provide very good access to palliative care are all essential to high-quality care for Canadians.

I note that Bill C-7 fixed the unconstitutionality of requiring a reasonably foreseeable natural death, removed the problem-causing 10-day waiting period and added an important waiver of final consent. Data to date suggests that the expected number of Canadians are accessing and receiving MAID, and that those who proceed with MAID are disproportionately advantaged versus socio-economically vulnerable. Well done.

Through my work, I've seen evidence of the distinction between what others might hope to conflate: MAID and suicide. Suicide is almost always a dramatic event, often violent, frequently impulsive, and usually carried out alone or in secrecy. It leaves devastation in its wake for families, for first responders and often for entire communities. By contrast, medical assistance in dying involves a legal framework, a rigorous process, the involvement of multiple health care practitioners and the option to involve many loved ones. I've witnessed the therapeutic effects of merely telling people they're eligible for an assisted death and have seen people live longer than they thought they'd be able to because they had this option. As a colleague so eloquently once stated, suicide implies some form of self-destruction, while assisted dying is a form of self-preservation. They're simply not the same.

This work was especially challenging in the beginning—no training and no guidance documents or standards. CAMAP and early practitioners filled that void, and while we're tremendously proud of all we've accomplished, I quote a colleague from just a few days ago lamenting the lack of practitioners in her region. She said, “The feds need to work with medical and nursing training programs, as well as provincial ministries of health, to address the limited provider/assessor issue, or these changes will be meaningless.” We couldn't agree more. Please read my brief for a review of the factors at play.

The establishment of a two-track system of access to MAID has led some practitioners to withdraw their services due to both a perceived and a real complexity, in process as well as patient population. CAMAP's federally funded Canadian-made curriculum project is an important and positive step toward helping correct the significant lack of standardization of care across the country. It will help set a standard of practice, and should provide both clinicians and the public some measure of confidence. However, a lack of accessible expertise and/or resources for patients continues to hamper practical efforts. Clinicians have begun to experience distress when faced with people who are eligible for MAID but whose suffering is primarily due to a lack of appropriate resources. We are not in any way suggesting MAID be curtailed due to the failings of our society, but we are strenuously suggesting that MAID and community resources for mental health, palliative care, and disability supports be developed and supported in parallel.

With my background in family medicine, I have seen the torment of families who are faced with the unbearable, the birth of a non-viable child or one with terminal illness, and I have journeyed with them. Mature minors in Canada already make their own health care decisions in the denial or acceptance of blood products or with regard to reproductive health choices, as examples. We already have experience in assessing their capacity to make independent decisions. In the catastrophic circumstance of a mature minor with an illness that is causing unbearable suffering, who in very rare cases might ask for access to MAID, to discriminate on the arbitrary basis of age seems indefensible and in fact blatantly cruel. Despite an initial discomfort, you might find a safeguard allowance of MAID for mature minors the most clear-cut of all the issues that you are considering.

I will leave the discussion of advanced requests to others, except to note that lack of availability is the concern I hear about at every presentation I have ever given on the topic of MAID. We would urge this committee to undertake a comprehensive review of past and current reports and recommendations, seek input from frontline clinicians, and make a decision about a matter that the majority of Canadians wish to see resolved.

As my final message, it remains unclear who or what is responsible for access issues. Is it the federal law or the provincial taxpayer-funded yet objecting facilities? As clinicians charged with doing this work, we are still far too few. Help train us. Compensate us and adequately resource our communities, or we will be unable to help people in the way you have trusted us to do.

● (1930)

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

With our third presentation, we have Tim Guest.

Mr. Tim Guest (Chief Executive Officer, Canadian Nurses Association): Thank you, Madam Co-Chair, Mr. Co-Chair, and members of the committee.

We are pleased to be invited to share with you the perspective of nurses on this important study. I'm speaking to you today from Mi'kma'ki, the ancestral and unceded territory of the Mi'kmaq.

My name is Tim Guest, and I'm a registered nurse and the chief executive officer of the Canadian Nurses Association. I'm joined today by Dr. Barbara Pesut, a registered nurse and a principal research chair in palliative and end-of-life care at the University of British Columbia.

CNA is the national and global professional voice of Canadian nursing, and we represent nurses across all 13 provinces and territories. Canada's 440,000 nurses touch the lives of patients at every point of care, and no provider has as much direct interaction with the public where complex human issues arise, such as medical assistance in dying.

Nurses have acquired significant knowledge and experience from nearly six years of MAID in practice and have valuable knowledge to share. In fact, nurses are the most consulted health care professionals when MAID practitioners are seeking to inform their assessments. Today, I will share key findings from a study conducted from Dr. Pesut on nurses' experiences with MAID, as well as some preliminary highlights of consultations conducted by CNA with nurses.

In 2017, Dr. Pesut and her team began a three-year study of Canadian nurses' experiences with MAID. The 59 nurses who were interviewed had diverse opinions about MAID, informed by different levels of engagement with cases. The study highlights how there is great variability in how MAID has been enacted in nurses' workplaces. Nurses emphasized the importance of teamwork in providing high-quality MAID care, although many worked without the benefit of a team.

Nursing work related to MAID is highly complex because of the need for patient-centred care in systems that were not always designed to support such care. Without adequate supports, some nurses chose to limit their involvement in MAID. The study concludes that without accessible palliative care, sufficient providers, a supportive team, practice supports and a context that allowed nurses to have a range of responses to MAID, nurses felt they were legally and morally at risk.

For its part, CNA held consultations in 2020 and 2021, in partnership with the Canadian Nurses Protective Society, with nurses involved in MAID. They provided insightful learnings of their experience, their expert opinion on MAID overall and the three special populations of mental illness as a sole diagnosis, mature minors and advance requests.

Nurses highlighted the lack of access to palliative care in Canada and the importance of scaling it up, as well as other types of services, to ensure that patients are not opting for MAID because of lack of access to acceptable alternatives. For example, we heard that limited access to primary care in rural and remote settings has led to patients directly reaching out to urban centres for MAID services. Furthermore, nurses stress the need to put in place strong safeguards to ensure the appropriate use of MAID for the three special population groups if MAID is expanded. We also heard that practitioners with appropriate expertise within these three groups need to be involved in the MAID process, although we recognize that this also brings concerns of creating barriers and limiting access.

Finally, we urge that if changes to the Criminal Code are brought forward, they are made in a way that safeguards and provisions are clear and include objective criteria. We need to ensure the practitioners can confidently interpret and implement the Criminal Code provisions.

In conclusion, the practice of nursing has been profoundly affected by the availability of MAID in Canada and the moral ambiguities it creates within the world of clinical practice. CNA heard from nurses that MAID can have an emotional toll on the clinicians who are providing it, particularly in areas with scarce resources and a lack of important alternative treatments, such as palliative care.

Thank you. We'll be happy to answer any questions.

● (1935)

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

Thank you to all of our witnesses.

We'll go right into round one, starting with Mr. Cooper for five minutes. I'll give a 30-second warning.

Mr. Michael Cooper (St. Albert—Edmonton, CPC): Thank you, Madam Co-Chair, and thank you to the witnesses.

I'm going to direct my questions to Dr. Pageau.

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

[*Translation*]

Dr. Félix Pageau: Thank you for your question.

That was part of the last section of my brief. I didn't have the time to read it all, because of the stress. I'm sorry.

Regarding autonomy, it must actually be exercised in context. We need the context, we need to know who is involved in the decision, what the environment is, and what the social and health context is.

Imagine that I asked you, three years ago, to make a decision concerning your end of life care. You would probably not have made the same decision as you would now, after the pandemic, after everything that has gone on in long-term care homes. Autonomy has to be exercised with the elements that are present in the decision.

Doing it in advance, we are not really in a context involving the exercise of autonomy. Advance medical directives, while we believe they promote autonomy, serve much more as a decision-making guide, that is, to guide the substituted decision. I am talking here about a substituted consent given by family or a decision that is, at best, much more benevolent and more beneficial for the patient.

So we are in a register that is not really one of autonomy, with advance medical directives, because we are not exercising autonomy in context; it is really autonomy at the time the decision is made. However, at that point, we don't know what is going to happen in the future. None of us is capable of predicting what will happen, especially not in a situation of dementia or evolving cognitive impairment. The context can always change, particularly in the case of geriatric care, as we have seen in recent years.

As geriatricians, we were aware that there were problems in long-term care homes, but the pandemic really revealed them to the public. Imagine if you had made a decision five or ten years ago. Would your decision have changed? That is what I would say about the context.

As well, the person also changes with dementia. The experience of dementia is extremely unsettling. It changes the lives of everyone around the person affected. We are not even talking about the same person anymore. The person has changed. They no longer exercise their autonomy, at that stage. It is very risky to permit medical assistance in dying in a context in which the person is not in a situation of autonomy, and is rather in a situation of substituted consent or even the benevolent decision of the medical or care team. It should not be permitted in that context.

That would be a seriously bad practice. I spoke about ageism, ableism and issues of discrimination and stigmatization associated with mental health problems. Even the decision concerning the use of medical assistance in dying in a dementia situation is very warped by all these components, which may be internalized by the person. In my opinion, this is not genuine autonomy. Autonomy must be exercised in context. The risk of including medical assistance in dying in advance directives is a very big one because, in medical terms, there may also be all sorts of elements that create conflicts of interest, for example the need to free up emergency beds, to allocate resources differently, and so on.

● (1940)

[*English*]

Mr. Michael Cooper: Dr. Pageau, I'm sorry to interrupt, but my time is limited. I will let you continue on with your answer, but when you speak about context, can you speak in the context of dementia and more specifically whether there are elements for someone who is suffering from dementia that are impossible to predict in the context of an advance directive? I think you were talking about that. Can you elaborate a little bit on that?

You mentioned the experience of the Netherlands, which, as I understand it, is one of the few jurisdictions that have advance directives. Were those advance directives being carried out in accordance with the wishes of the patient when the advance directive was brought? Can you speak to those issues?

[*Translation*]

Dr. Félix Pageau: In fact, most of the time, advance medical directives are difficult to apply, given that when they are prepared the person is not necessarily given guidance. The context is then hard to apply. When the requests are made, we often hear much more what the family is telling us.

A study done in Quebec by a group led by Ariane Plaisance shows that people don't know what medical assistance in dying or advance medical directives really are. When they are asked whether they want medical assistance in dying, they understand that we are asking them whether they want good palliative care.

[*English*]

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

Next we have Mr. Maloney for five minutes.

Mr. James Maloney (Etobicoke—Lakeshore, Lib.): Thank you, Madam Chair, and thank you to our witnesses.

I'm going to start with Dr. Green.

Dr. Green, I saw you recently on *The Fifth Estate* when you were talking about MAID. I was interested in some of your comments there.

I'm going to pick up on something you mentioned in your opening remarks. Talking about mental health issues, you distinguish between suicide and MAID. I take it that you're very clearly in the camp of allowing MAID for people who have mental health issues.

Dr. Stefanie Green: I'm just going to say that you shouldn't make assumptions.

I'll take the question. Do you want me to answer that first?

Mr. James Maloney: Yes, please.

I didn't mean to assume. If my interpretation was wrong, please straighten me out.

Dr. Stefanie Green: Certainly as the representation of CAMAP, I'm always careful.

Our organization does not advocate MAID in any particular patient population. We advocate the highest level of care under the current law. If our law is to allow mental health patients to access MAID in 2023, then we will do our very best to accommodate that, with the recommendations of the expert panel. We look forward to that.

I don't know that my preference or my beliefs are of import, really.

Mr. James Maloney: Your opinion is of import, Doctor. I'm curious to know whether you think the legislation that's coming into force in 2023 is correct. Should we allow MAID for people with mental health disorders, in your opinion?

Dr. Stefanie Green: Well, to be honest, it's a legal question. I think it's discriminatory to tell people they're not allowed to access MAID based on a diagnosis.

I understand that decision. I'm in favour of following the decision of the House of Commons and the Senate. I'll do my best to provide the highest level of care for those patients. Certainly I'm not going to withdraw my services because of that.

Mr. James Maloney: Thank you, Doctor. I respect that. I'm a lawyer, so I will follow the law too, but I often rely on the advice of medical practitioners in determining what's right and what's wrong. I think that's why we're here.

You are somebody who has extensive experience in this area. I think it's a fair question to ask you whether or not you would be supportive of the law that's coming into force in 2023. If you're not comfortable answering that question, I'll move on.

● (1945)

Dr. Stefanie Green: I'm comfortable saying that I'm comfortable to provide MAID to mental health patients who fulfill the criteria of the law, absolutely. I would not withdraw my services there.

Mr. James Maloney: Okay.

Here's my concern when it comes to mental health. I have some experience dealing with doctors. If you showed 10 doctors an X-ray or a CAT scan of somebody who has cancer, all of them will agree the person has cancer. If you have 10 people examining somebody with a mental health problem, there's a chance that two or three of them will reach the conclusion that the person does not have a mental health problem.

Does that analysis cause you concern or should it cause me concern, in your opinion?

Dr. Stefanie Green: To be honest, I think when mental health patients start to step forward for this care, we're going to have to be very careful with how we assess them.

I think it's valid to think we're going to need more expertise. We're going to need more consultations. We're going to need to be very careful, and maybe it'll be different from what we're doing right now.

I do actually have faith in the physician and nurse practitioner community to do their jobs properly. I think we can assess capacity. I think we can assess whether they have a diagnosis or not. I think we can assess suffering. We've done that before there was MAID. We do that now that there is assisted dying. I think we'll be able to do that in that population. I'm confident we'll be able to do so.

Mr. James Maloney: I have faith in the profession as well, but on the off chance that somebody is wrong, we're talking about the most dire of consequences here.

Let me move on to mature minors, because I have the same concern there. It requires a subjective assessment by a doctor or doctors to determine whether somebody is in fact mature enough to make a decision. You used the example of making decisions on reproductive health. Do you agree that you run into the same problem making an assessment about whether somebody is mature enough to make that decision?

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

Dr. Stefanie Green: No, I would disagree with that. I think we have lots of experience determining whether minors have or do not have capacity to make their own decisions. We've been doing that for decades.

We certainly have experience in reproductive health choices, in blood products and in lots of different circumstances. Although it's always tricky, I think we have experience and have shown that it can be done safely and carefully. I think that can absolutely be done. I don't think it's subjective. I think it can be objectively determined.

Mr. James Maloney: Thank you, Doctor. Your comfort gives me some comfort, so I appreciate your answers.

I'm out of time. Thank you.

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

Monsieur Thériault, you have five minutes.

[*Translation*]

Mr. Luc Thériault: Thank you, Madam Chair.

First, to facilitate the committee's work, we should agree on the use of terms. At present, we are using advance medical directives, or AMD, to refer to an advance request for medical aid in dying. Advance medical directives do not present a problem. They are part of agreed medical practices of refusing and stopping treatment. If we constantly confuse advance requests for medical assistance in dying and advance medical directives, it won't work, conceptually. We need to agree on this.

Dr. Pageau, in your defence, you didn't have a lot of time to explain your thinking. I understand there is an obligation to be very careful about various pitfalls such as ageism, for example. You seem to think that in its desire to facilitate access to medical assistance in dying or to extend it to certain situations, the state is operating on reasoning based in malice.

But when we violate a person's autonomy, their free will, their capacity to make their own decisions, their free choice, then, in my opinion, we are offending their dignity, as Kant meant it. You point out in other texts that death is not beautiful, it stinks. That has nothing to do with incontinence.

By definition, the health care system, the medical profession and health care workers must be benevolent. If they are malicious or harmful, they have to be got rid of, period. That is provided in the Criminal Code. We can't be benevolent, as a state, if we violate a person's autonomy. When a person is suffering from fatal dementia, in the name of what would the state have the right to define its threshold of what is tolerable? In your opinion, how is it more honourable and ethical?

● (1950)

Dr. Félix Pageau: You are correct that Kant based autonomy on the concept of dignity and human value. They are two slightly different concepts. Autonomy is the rational capacity to make one's own decisions, but benevolence is not necessarily aligned with autonomy. Some authors do say that it is malevolent not to respect autonomy and benevolent to respect it. In their classical sense, these two principles are very different: a person's autonomy can be infringed while doing good.

Instead, I want to point out here that in dementia, autonomy is lost. The autonomy exercised in advance medical directives or in everything that is a previous guide is a way of representing autonomy in the future. That autonomy cannot be fully exercised because the person is not aware of what is happening. At that point, we are in the register of benevolence.

The state does not prevent people from being well by preventing them from having access to medical assistance in dying; the opposite is true, in fact. My argument is, rather, that if we permit medical assistance in dying, we run the risk of encouraging people to believe they no longer have value, they are bad, they stink—that's the word you used—when they suffer from advanced dementia and are sometimes lying in their own excrement, unfortunately. We clean them, we look after them, we care for them. That care is beneficial because the previous autonomy no longer exists...

Mr. Luc Thériault: Forgive me for interrupting you.

How would intervention or prohibition by the state be more honourable and more ethical? In the name of what could the state tell someone who is of sound mind and has received a firm diagnosis not to make that choice? Supported by a caring and benevolent team, the person says that when they have reached a particular condition, they have crossed the threshold of what is tolerable and they are longer capable of acting, they will want to be given medical assistance in dying. In fact, suicide has been decriminalized, I would note in passing.

How is that ethically blameworthy?

Dr. Félix Pageau: There is a logical problem in what you're saying. When a person gets to the point of requesting medical assistance in dying, autonomy is no longer being exercised. Even if they made a previous guide, the benevolence and choice of other people is all that applies for us, unfortunately or fortunately. Unfortunately, if we believe that dementia is a condition of terminal decline for which care should not be given...

Mr. Luc Thériault: In the name of what could the state...

[*English*]

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

I'm going to go on to Mr. MacGregor for five minutes.

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

Dr. Green, I'd like to start with you.

In the motion that the House passed authorizing this committee to start its work, one of our main topics is going to be the protection of Canadians with disabilities. I was furiously scribbling notes as you were making your opening statement, and I do know that you made reference to the necessity of disability supports.

I have heard concerns, and I'm sure many of my colleagues have, from commentators who've said that MAID could be requested by vulnerable populations because of a lack of supports to ensure an adequate quality of life for individuals who may be sick or may have a disability. With those concerns that have been expressed in mind, I'd like to ask you if you can talk about any encounters in your practice or in that of any of your colleagues with individuals who have sought MAID and whose requests seemed to be based on a lack of supports. If so, how did you or your colleagues advise those individuals?

Dr. Stefanie Green: I won't talk about any particular cases, because there are still very low numbers of people from the track two coming forward, and even less in the circumstance you describe, though I'm sure it's not zero.

I think what we are starting to see, as I mentioned, are people coming forward who have expressed that their suffering is extreme and intolerable and the feeling of the clinician involved is that perhaps improved resources might alter that and improve and lessen their suffering if the resources were available.

That's not necessarily coming from the patient. It may be, and it may be that they've expressed that they haven't been able to access something, but it's coming from the people who are doing the work and the assessments and who are noticing that maybe this patient hasn't had access to a pain specialist, we'll say, because they live somewhere rural where there is no pain specialist.

The interesting dilemma is, what do we do in a situation when someone truly meets the criteria of eligibility for MAID but the clinician believes that maybe something more could be offered that's not actually reasonably available to that patient? That's causing distress in some of my colleagues, and we are not moving those cases forward, but we do ask that the government, federally and provincially, help to fix that situation and help make more robust the resources that can be made available.

We can't fix the health care system as clinicians, necessarily, and we certainly do not suggest that we curtail MAID in general, but we do think that you cannot hold individuals hostage to society's failings and the health care system's failings. That's just not fair. That is why we support the parallel development of resources—and adequate resources—at the same time that MAID is being developed and supported.

● (1955)

Mr. Alistair MacGregor: Thank you.

Do you think the trend could increase? In your mind, what kind of a gap do you think the federal and provincial governments are looking at trying to properly address, so that you and your colleagues no longer need to worry about those additional situations in a person's life and you can focus solely on the clinical aspects of a person's case?

Dr. Stefanie Green: I wouldn't presume to be able to answer that.

Mr. Alistair MacGregor: No.

Dr. Stefanie Green: It's been just a year since we've had these patients coming forward, and very few of them. Ideologically, I can tell you that I've been in the health care system for several decades, and there are many gaps in our health care system. I don't think we need MAID to point that out. I imagine the gaps are substantial in some areas and minimal in others. I think it's too soon for me to be able to answer that from the perspective that you'd like.

Mr. Alistair MacGregor: I appreciate that. Thank you.

In the final minute that I have, I'll turn to you, Mr. Guest.

From the perspective of the Canadian Nurses Association, if you wanted to add a little more about your experiences with the issues of accessing MAID in rural, remote and northern communities and, in your mind, how that access can be improved, is there anything you wanted to add in your testimony to the committee?

The Joint Chair (Hon. Yonah Martin): You have about 35 seconds.

Mr. Tim Guest: Thank you for the question.

Based on our consultation with nurses, some of what is concerning is that there's a lack of equity in accessing assessors or providers for those services.

The other thing we've also run into when we've had conversations with nurses who work in those areas is the concern that individuals may choose to access those services sooner than normal because they're unable to access other services that would enable them to delay those decisions.

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

We'll go to questions for senators.

Mr. Co-Chair, I will turn this back to you.

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

[*Translation*]

We will now move on to the period for questions from senators.

We will start with Senator Mégie.

Senator, you have the floor for three minutes.

Hon. Marie-Francoise Mégie (senator, Québec (Rougement), ISG): Thank you, Mr. Chair.

Thanks to the witnesses for being with us today.

Dr. Pageau, do you practice medical assistance in dying?

Dr. Félix Pageau: No, I don't practice it.

Hon. Marie-Françoise Mégie: Right.

What would you say to someone who is 55 years old who has cared for their parents throughout the process of the evolution of dementia, up to the final phase, who says they don't want to go through the same thing and decides to make sure they can receive medical assistance in dying once they are unable to recognize their children, for example?

What do you do when a person confides this in you? Do you try to dissuade them? What do you say to them?

Dr. Félix Pageau: It's interesting that you asked me the question, because I had a discussion about this today with my nurse. Her work consists of looking after people with dementia. Her argument was that we don't have adequate care. She doesn't want to depend on malevolent people, who are sometimes in long-term care homes, or LTCHs, or in homes for the aged. Her fear was of finding herself in a context of malevolence, that people would give her poor care, that they would have contempt for her or not offer her adequate care.

In fact, my patients are all over age 65. However, it is frequently the case that our patients' children make this kind of request. Often, they have been looking after their family members for a long time, they have become very worn out and they see dementia as a pretty heavy burden to bear. They don't want their family to experience the same thing. I understand that.

The care to provide for persons suffering from dementia calls for a lot of resources and involves very specialized care. There are different types of dementia. There is what some call “happy dementia”, which doesn't call for a lot of care. However, when behavioural problems and psychological problems are associated with dementia, it calls for very specialized care. People who are not trained in this field may indeed find the situation extremely difficult. They project it onto themselves and tell themselves that their family members didn't receive the care they needed and they don't want to experience that. That is where the fear of decline comes into play, that I was talking about a little earlier. They decide to request medical assistance in dying for themselves, because they internalize that vision of ageism and ableism. They don't want to be disabled or aged in Canadian society as it now is and they especially don't want to suffer from a mental illness in Canadian society as it is now. Canadian society is in fact very stigmatizing, and even contemptuous, for people who have challenges in their daily lives.

In geriatrics, my area of expertise, and in geriatric psychiatry and palliative care, if people receive good care, they could be well and get better and no longer be seen as a burden by their family. The family could then regain its place, whether we are talking about children, spouse or family caregiver. People should not have to carry this mental load on an everyday basis.

I understand this fear of decline and desire to avoid it, but as I told my nurse, we have to fight and talk to the government to get improvements to geriatric care and geriatric psychiatric care and palliative care in Canada. Improving care would make it possible to reduce the fear of decline that people in their fifties often talk to us about.

● (2000)

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

[*English*]

Next is Senator Kutcher.

Senator Kutcher, you have three minutes.

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

My question is for Dr. Green.

We understand that your organization is working to create a national MAID assessment and intervention program that will have the impact of standardizing MAID delivery across Canada, and additionally, through the process of certification, create comprehensive and high-quality standards for health providers who deliver MAID. Could you please tell us more about this work, including what organizations are involved, who is providing the certification and what the certification will achieve? Do you think that this outcome will, over time, create a recognition for MAID provision similar to that which has been recently developed and is now available for palliative care?

Dr. Stefanie Green: Thanks for the question.

CAMAP is particularly proud of our development of this particular program. This is a national program that is federally funded by Health Canada. It is a multi-year program. It is meant to help clinicians who are new to the field as well as those who are already in the field looking to expand their skills.

This is a very large program. I think our team kickoff included about 90 invitations. There are currently, from the ground up, eight working groups. They are diverse from a geographical point of view, from a medical and nursing background point of view and from an EDI lens. They are each working on a module that will contribute to the overall curriculum.

These working groups are accountable to an executive committee of leaders of each of those working groups. They are then overseen by both the CAMAP board and, perhaps more importantly, a national stakeholder committee that is made up of 17 different national member organizations, each of which is a significant stakeholder in MAID in this country. I will not name all 16 of them for you, but they include the Royal College of Physicians and Surgeons of Canada, the Canadian family practitioners association, the CNA, rural physicians, indigenous representation, palliative care, psychiatry and the Collège des médecins du Québec. It's quite a diverse group. There's quite a bit of oversight. We have a project team of three full-time staff.

Again, this project will last until 2025. At the end, we will have seven modules that are online, off-line, synchronous, asynchronous, bilingual, easily accessible and fully accredited by the national organizations, including the family practitioners, the royal college and the nursing association, which have already committed to helping us achieve that proper accreditation.

We are not looking at credentialing. We will not be applying letters after the names of the people who complete this course, but they will be able to point to this curriculum to say that they have completed it. We hope that this will in fact help with the standardization issue across the country, which is significant at this point, and help build confidence in both the clinicians and the public.

I hope I have answered your question.

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

[*Translation*]

Senator Dalphond, you have the floor for three minutes.

● (2005)

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

My question is for Dr. Pageau.

Dr. Pageau, since you work in geriatrics, your youngest clients are my age. In the case of a person who has made advance medical directives and who, by definition, is no longer able to make decisions for themself, substituted consent is given. The physician speaks to the family.

Would you, yourself, refuse to speak to the family and to act on advance medical directives?

Dr. Félix Pageau: I am not opposed to it, because advance medical directives are the law. So I have to follow them. I comply with the law, but I still believe that we have to avoid including medical assistance in dying in directives that are so coercive, legally speaking. In my opinion, there is no autonomy possible in advance medical directives or advance euthanasia directives. That goes with what I was saying earlier about any document that legally compels the medical team to provide a precise type of care, contrary to the advance medical directives, which prevent the physician or care team from doing things against the person's will. Medical assistance in dying would be included as a mandatory directive to be followed. So the physician is being required to perform an act.

This is the subject I first feel uneasy about. We have to consider that in many cases, people are not give adequate guidance and don't properly understand what medical assistance in dying, advance medical directives or advance euthanasia directives consist of. Experience in the Netherlands also shows that the directives are often not reliable, they don't really align with the context or practice, and people did not always include elements that really made sense for them.

A person may think that because they have expressed their wishes in advance, it will be reliable, coherent and enforceable. However, it does not always express the person's experience well. When the actual situation arises, we find that directives are not always reliable, coherent and enforceable. My unease is due to the fact that we find ourselves dealing with something mandatory and incoherent, that is sometimes neither reliable nor comprehensible.

My unease relates most importantly to ending the days of aged persons suffering from dementia, very vulnerable persons who have not made an informed decision. It may be that the document wasn't reliable and they made a flawed decision. In my opinion, to kill someone, we must be pretty certain that it is what the person wants.

I said I don't practise medical assistance in dying, because a majority—

Hon. Pierre Dalphond: When you decline to revive someone, you are still allowing them to die.

Isn't that right?

Dr. Félix Pageau: That's right. I want to add, however, that death in itself, not providing care, not using heroic measures or providing futile care, doesn't cause me any problems. Passive euthanasia, supporting people in death while respecting their dignity, is not a problem for me.

I find that for autonomous people who are experiencing extreme suffering, medical assistance in dying can be an appropriate treatment or medical act. On the other hand, if the person is in a state of advanced dementia and is no longer autonomous, we are no longer in the same register at all. As I said, there are risks of significant bad practice. In the Netherlands, for example, euthanasia was imposed on a woman who was in a state of happy dementia.

The Joint Chair (Hon. Marc Garneau) : Thank you, Dr. Pageau. I'm sorry to interrupt you.

[*English*]

We will now go to Senator Wallin.

Senator Wallin, you have three minutes.

Hon. Pamela Wallin (Senator, Saskatchewan, CSG): I'm sorry. I think there was crosstalk there, but if you're asking me to go ahead, I will. Thank you.

Before I ask my questions I'm wondering whether, Mr. Pageau, you would provide any evidence from the Netherlands about cases of people who have been forced against their will to, I think you said, sign documents. People aren't generally asked to sign documents. They actually have the right to choose it or request it. If you have specific examples and it constitutes evidence, I'd like to hear it.

My question is for Dr. Green.

As we heard from our witnesses earlier, of course no one can predict the future, but we do this all the time in health care. We opt to have surgery when we may not know the outcome. We opt for “do not resuscitate” orders in the case of future accidents or conditions that may arise; we don't know what the details are, but we ask for that.

In the case of cognitive decline, we know the outcomes are inevitable. There is a resulting physical decline. We know that's inevitable. What's harder to deal with than this fear of decline is the fear of being denied the right to have any choice or any control over your health outcomes, which we respect in these other cases. Are you concerned that it in fact can hasten the decline of cognitive status and physical status in some cases? Also—and there are cases of this that I'm aware of—some people then choose to end their lives earlier, because they fear the inability to make a choice or to be allowed a choice later on.

● (2010)

Dr. Stefanie Green: Thanks for the question.

There are a couple of parts. If I forget some, please remind me.

I do think that we've had precedents. We've had experience in the past five years before the amendments. We saw patients who were nearing the end and were really fearful of losing the capacity to make the choice to go ahead with assisted dying. That was causing tremendous anxiety in patients and their families, to the point that we were able to give that feedback to the government. They heard that story and created the waiver of final consent for very specific populations so that they would take their medications or pain medications at the end of life and they would not withhold that from themselves in fear of losing capacity.

I think there is evidence of patients making premature choices out of fear of what's to come or fear of loss of ability to make those choices or fear of losing control. We've heard lots of talk today about advance directives. I think it has been very well established in medicine for decades now that patients do have the right to give an advance directive for their care in situations that they may not fully understand at the time, such that if they were found to be on life-sustaining medication or were being ventilated, they might choose to have that removed. They could make that choice now, clearly, in a document that we all agree must be respected. I think we have good precedents for advance directives of some sort.

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

We'll go to the last senator. Senator Martin, you have three minutes.

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

My question is for Dr. Pageau.

I'm that 57-year-old who had a mother with dementia for 12 years. She had palliative care for less than two weeks, so I saw a very.... When I say “positive”, I saw my mother live her life to the fullest to the best of her ability. Had she not done that, I know that out of my fear, if an advance directive or discussion of advance directive and MAID were given to me, I may choose to have such a directive because of this very terrifying experience with my mother.

Would you speak a little bit more about the importance of the timing? When should directives and MAID be discussed? I can see as a 57-year-old what I might have chosen had my experience been different.

[*Translation*]

Dr. Félix Pageau: I don't know whether I should answer the previous question about evidence. In my brief, I cited the study by Ms. de Boer and the Council of Canadian Academies, which reviewed the scientific case literature. It includes the case of the person I spoke about earlier, in the Netherlands. So you could consult my brief.

Regarding dementia, I find it extremely sad that medical assistance in dying is considered to be preferable to the palliative and geriatric care offered in Canada, as was the case for your mother. That is exactly what I want to bring into the debate.

I understand your sadness, because families and the people who care for the aged tell me exactly the same thing as you. Instead of choosing health care, patients prefer to receive medical assistance in dying or active euthanasia, as we practice it here, much more often than assisted suicide. The system is ageist and does not promote the best interests of the patients and greater benevolence toward them. There is still a lot of organizational mistreatment, physical and otherwise, in our health care systems. Medical assistance in dying seems to be a solution. But in my opinion, the solution consists not of eliminating patients, but of caring for them.

[*English*]

The Joint Chair (Hon. Marc Garneau) : You have 30 seconds.

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

We'll go to the second round for the members.

I'll call on Mr. Cooper once again for three minutes.

The Joint Chair (Hon. Marc Garneau): Co-Chair, we're going to have to proceed to the second panel at this point. We've done our one hour.

● (2015)

The Joint Chair (Hon. Yonah Martin): I see. All right....

The Joint Chair (Hon. Marc Garneau): I can wrap it up by saying thank you very much to our witnesses.

Thank you for your input this evening. Thank you for answering our questions.

[*Translation*]

We are very grateful. What you have to tell us is very important in view of the work we will be doing over the next few weeks.

Thank you for being with us today.

[*English*]

With that, I would like to suspend very briefly as we transition to panel number two.

● (2015)

____________________(Pause)____________________

● (2015)

The Joint Chair (Hon. Marc Garneau): We're now starting panel number two.

Welcome to our two witnesses.

Before speaking, I would ask that people wait until the co-chair recognizes you. All comments should be addressed through joint chairs. When speaking, please speak slowly and clearly to allow for translation.

Interpretation of this video conference will work like an in-person committee meeting. You have the choice at the bottom of your screen of either “floor”, “English” or “French”. When you are not speaking, please mute your microphone.

With that, I'd like to welcome our witnesses for panel number two. We have Dr. Leonie Herx, chair and associate professor, palliative medicine, Queen's University and chair, Royal College specialty committee in palliative medicine,

[*Translation*]

We also have with us Dr. Alain Naud, a family and palliative care physician.

Thank you both for joining this group this evening.

I am now going to invite each of you to give a five-minute presentation.

[*English*]

We'll begin with Dr. Herx.

For you introductory remarks, Doctor, you have five minutes.

Dr. Leonie Herx (Chair and Associate Professor, Palliative Medicine, Queen’s University and Chair, Royal College Specialty Committee in Palliative Medicine, As an Individual): Good evening. Thank you for the opportunity to speak on palliative care as it relates to the statutory review of Canada's current medical assistance in dying legislation.

I am speaking to you today as a settler on the traditional territories of the Haudenosaunee Confederacy and the Anishinabek Nation. I am grateful to be able to live, learn and play on these lands.

My name is Dr. Leonie Herx. I'm a specialist palliative care physician; head of palliative medicine at Queen's University; medical director of palliative care at Kingston Health Sciences Centre and Providence Care Hospital; the immediate past president of the Canadian Society of Palliative Care Physicians, where I have been a peer-elected member of the board of directors for the past nine years; and the chair of the Royal College specialty committee in palliative medicine.

Palliative care is a holistic approach to care that focuses on enhancing the quality of life for persons living with life-threatening illnesses and their families by means of early identification and impeccable assessment and treatment of symptoms, including physical, psychosocial and spiritual concerns. It supports a person in living well until they die. It is medical assistance in living, or MAIL, if you will. Palliative care does not hasten death and is internationally recognized as a practice that is distinct from MAID philosophically, clinically and legally.

Only about 30% to 50% of Canadians who need it have access to some kind of palliative care of unknown quality, and very few, only about 15%, have access to specialist palliative care to address more complex issues. You are less likely to receive palliative care if you are poor, indigenous, homeless, incarcerated or living in a rural area.

Studies from around the world have shown that early integration of palliative care improves quality of life, reduces anxiety and depression, reduces caregiver distress and may even help people live longer. An integrated palliative approach to care should be provided as part of the management of all serious illness, starting soon after diagnosis. However, due to the ongoing stigmatization and misunderstanding of palliative care as end-of-life care, we are often only involved much later.

When patients' palliative care needs are not met, the ensuing physical, emotional and spiritual suffering can lead them to feeling depressed, hopeless and a burden to others, which are many of the factors driving requests for MAID. Earlier palliative care can alleviate suffering before it becomes irremediable. Failure to do so, as asserted by Dr. Romayne Gallagher and colleagues, should be seen as medical error.

MAID was established for exceptional circumstances, not as a routine procedure for ending life as a solution to suffering that could be addressed through health and social supports that help people live a dignified life. Since Bill C-7, we now see countless cases in the media, and in our own medical practices, of people requesting and receiving MAID due to a lack of basic supports needed for living, including a lack of palliative care, home care and disability care.

Health Canada's annual report on MAID shows that a significant number of people receiving MAID, 15%, had no palliative care at all, or that palliative care came much too late, with 18% receiving it within two weeks of receiving MAID and 19% within four weeks of the request. Another 3% are unknown. At least 35% of those receiving MAID had little to no palliative care. This is consistent with a Canadian study by Munro in 2020, which showed that 40% of patients had no palliative care prior to requesting MAID. This should be seen as a failure of our health care system. With removal of the 10-day waiting period under Bill C-7, these numbers are likely to increase further, because the impetus to call palliative care is not there.

In Carter v. Canada, the Supreme Court of Canada discussed what possible impacts implementing a law for assisted death prior to securing universal access to palliative care might have on the development of a strong palliative care system. With almost six years of lived experience now, we have seen significant deleterious effects of the impact of MAID implementation on palliative care practice, including diminished resources and increasing distress experienced by palliative care clinicians. I will provide some examples.

Some health authorities incorporated MAID into palliative and end-of-life care program roles. This has led to palliative nurses leaving their jobs because they felt unable to provide palliative care. In Ontario, some hospice palliative care nurse practitioners are using their paid full-time palliative care roles to provide MAID.

Palliative care clinicians are having to spend a significant amount of time on administrative issues related to MAID, which takes away from time to provide palliative care.

There is decreased access to specialized palliative care beds when health authorities require hospices and palliative care units to admit patients for the sole purposes of administering MAID.

We see increasing moral distress in palliative care clinicians from forced participation in MAID, due to some health authorities mandating that hospices and palliative care units provide MAID or lose their funding. This is resulting in retention difficulties and early retirements from palliative care, which is accentuating and accelerating the already critical shortage of specialist and generalist palliative care physicians.

We also see patients who are unwilling to access palliative care because they associate it with MAID and are afraid that palliative care will hasten their death or that MAID will be provided without their consent.

● (2020)

Patients are accessing MAID due to a lack of palliative care provision. Patients are requesting MAID because a trusted physician suggested it to them—

The Joint Chair (Hon. Marc Garneau): Dr. Herx, you'll have to wrap up very quickly.

Dr. Leonie Herx: Sure. I have 10 seconds.

Currently, Canadians have a right to medical assistance in dying but not to medical assistance in living. Having accessible, high-quality palliative care needs to be a universal right in Canada.

Thank you.

[*Translation*]

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

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

Dr. Alain Naud (Family and Palliative Care Physician, As an Individual): Thank you very much, Mr. Chair.

I would first like to thank the committee members for offering me the opportunity to tell them about my experience and my observations concerning medical assistance in dying.

I have been a family and palliative care physician for 37 years. I was an expert witness on medical assistance in dying and palliative care at the trial of Ms. Gladu and Mr. Truchon in 2019. The other details about myself are in the 18-page brief I filed with the committee earlier. The brief contains a number of references to various documents and reports that I invite you to consult. In it, I refer to the current situation and address the issue of expanding access to mental health for minors and, more specifically, of advance requests after a diagnosis of Alzheimer disease or other major neurocognitive disorders.

After more than six years' experience with medical assistance in dying in Quebec and nearly as long in Canada, there is a clear finding that the famous slippery slope promised by opponents has never happened and that medical assistance in dying is administered stringently and in complete compliance with the law.

Medical assistance in dying is a form of medical, moral, ethical, legitimate and perfectly legal care. There is no conflict between medical assistance in dying and palliative care; quite the contrary. With palliative sedation and refusal of treatment, these are interrelated and complementary end of life options, the choice of which belongs exclusively to a patient who is competent and well informed. In Quebec, approximately 80 per cent of patients who died after receiving medical assistance in dying were already receiving palliative care. The remaining 20 per cent refused palliative care, and were perfectly entitled to do so.

I am now going to talk about Alzheimer disease and advance requests. This is the first expansion of access that has long been awaited by an undeniable majority of the public and on which there is a broad consensus. Two Canada-wide surveys conducted in 2019 and 2021, respectively, that are referred to in my brief, showed that 85 per cent of Quebeckers and 80 per cent of Canadians wanted directives of this kind.

In Quebec, a group of independent experts retained by the government to study the issue from ethical, clinical and legal perspectives worked for two years, from 2017 to 2019, and submitted a report that recommended, at the end of a remarkable exercise in consideration and documentation, that advance requests be made available. The reference to their exhaustive report, in French and English, is available in my brief. On that subject, my brief also gives references to the Quebec forum that was held in January 2020 and to the report of the special committee of the Quebec government that was submitted in December 2021 and also recommended instituting advance requests.

I refer to a survey of physicians and the public done by the Collège des médecins du Québec, and most importantly to the position of the Collège, approved by its board of directors in December 2021, regarding advance requests, mental health and minors.

I comment at length on happy dementia, which is sometimes cited by certain people to oppose advance directives, and in my brief I propose a mechanism and safeguarding measures to put in place that are based on the choice, by the person themself, of observable and objective signs of the seriousness of the illness when the person reaches the stage of incapacity, and not on a clinical stage. These directives must absolutely be mandatory and not subject to veto by family, as is already the case for mandates in the event of incapacity, wills, and, in Quebec, the Registre des directives médicales anticipées.

Advance requests have to be made accessible to avoid some patients with Alzheimer disease committing suicide. That is a little known fact, but it happens. I am thinking of the stories of three public personalities.

On the question of vulnerability, I refer to the judgment of the Superior Court of Quebec in the Gladu and Truchon case. The Court heard numerous experts over two months, analyzed voluminous evidence, and concluded as follows:

> 1. Medical assistance in dying as practised in Canada is a strict and rigorous process that, in itself, displays no obvious weakness
>
> 2. The physicians involved are able to assess the patients' capacity to consent and identify signs of ambivalence, mental disorders affecting or likely to affect the decision-making process, or cases of coercion or abuse;
>
> 3. The vulnerability of a person requesting medical assistance in dying must be assessed exclusively on a case-by-case basis, according to the characteristics of the person and not based on a reference group of so-called "vulnerable persons". Beyond the various factors of vulnerability that physicians are able to objectify or identify, the patient's ability to understand and to consent is ultimately the decisive factor, in addition to the other legal criteria;

I invite you to read that remarkable judgment, which is available in English.

On the subject of mental health, I address the reasons, based on experts' reports, why mental health cannot be excluded from eligibility. It is important now that we consider the guidelines to be put in place, before the expiry of the deadline for Bill C-7.

To conclude, on the question of minors, I again rely in my brief on the position of the Collège des médecins du Québec, which I endorse in its entirety, on experience since 2002 in Belgium and the Netherlands, in particular with its Groningen Protocol, and on the 2018 document of the Canadian Pediatric Society. That society conducted a survey of Canadian pediatricians that clearly shows that pediatricians here receive requests for medical assistance in dying and discuss this subject with young people and their parents.

● (2025)

I illustrate this with a situation that occurred in Quebec. Last year, a young man died at the age of 17 years and nine months of a very aggressive cancer and he would have liked to receive medical assistance in dying. He was unable to get access to that because he was three months short of being entitled to it.

Thank you again for inviting me to appear before the committee.

I am available to answer your questions or any questions you might have after reading my brief.

● (2030)

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

[*English*]

We'll now proceed with the first round of questions. I'll transfer back to my co-chair, Senator Martin.

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

We'll begin with questions by Michael Barrett for five minutes, please.

Mr. Michael Barrett (Leeds—Grenville—Thousand Islands and Rideau Lakes, CPC): Thank you, Co-Chair, and thanks to the witnesses for appearing here today.

My first question is for Dr. Herx. I was interested to hear you reference the number 35% as those who accessed MAID but didn't have access to palliative care. We recently heard testimony, Doctor, from a witness who was here as an executive adviser on behalf of Health Canada, Ms. Abby Hoffman. Her position on behalf of Health Canada was that most people who have had MAID had palliative care. What's your response to that, Madam?

Dr. Leonie Herx: Thank you for the question, Madam Chair.

There's a really significant problem with the data that's being collected by Health Canada, which was reported by Ms. Hoffman. I did listen to her testimony and I'm very aware of the Health Canada reports. Those rely completely on self-reporting by MAID providers, and there is no ability right now in Canada to measure the quality or quantity of palliative care that is being provided or to know who is providing it. We do not have any standards or ability to collect data nationally, as we can for MAID statistics. Unfortunately there is no ability to make those conclusions.

We know that clinicians have a large misunderstanding about palliative care and don't understand how it can make such a difference in someone's life early on to prevent getting to the point of irremediable suffering. How palliative care is explained to patients when they request MAID is only as good as the person who is giving the explanation. We know that patients often get wrong information and have a very limited understanding.

I think one of the biggest problems is that if you're only hearing about palliative care when you get to the point where you're asking for death, then we have a big problem, because we failed upstream to treat the problem in the first place. That's the part that we need to focus on.

There is so much suffering that's not being alleviated because palliative care is not readily available to patients when they need it, when they start having symptoms and suffering because of serious illness. It needs to be integrated early into chronic illness, and right now, in our very best data, which is subjective reporting by MAID providers who may not understand what's involved in palliative care, we're seeing 35% of people have palliative care maybe within two weeks of their request, which is probably much too late, or maybe receiving none at all. Even four weeks prior to the request, I would say, is inadequate to prevent irremediable suffering.

Mr. Michael Barrett: I don't want to infer something that you weren't intending with your remarks. Could you just clarify very quickly, if you wouldn't mind, what you think about the claim from that same witness or that same testimony that there are very few cases of non-compliance per year?

Dr. Leonie Herx: We cannot draw the conclusions. We do not have the data to draw those conclusions.

Mr. Michael Barrett: Okay.

I believe that you said—and pardon me for paraphrasing—that palliative care does not hasten death and is internationally recognized as a practice distinct from MAID. Can you comment on the specific statement by Health Canada in that same testimony in our last meeting that MAID and palliative care are not separate?

Dr. Leonie Herx: Yes, absolutely.

The national palliative care organizations, including the colleges that are responsible for setting the competencies for the certified training programs, including a two-year Royal College program in palliative medicine and a one-year College of Family Physicians program, are much different from the continuing medical education modules we're talking about for MAID. Those certification programs and the national bodies for palliative care and the international organizations recognize that palliative care does not hasten death at all. It accompanies people through suffering and helps them live well until they die.

The difficulty we are experiencing in palliative care is that MAID has been forced into that care by health authorities and non-palliative experts who've said that you have to provide it in your hospices and your palliative care units, and that is forcing us to be involved. That's also a bit of a misrepresentation, I think, that Health Canada reported. They're not completely separate because they've been forced to go together by external authorities who are not experts in palliative care.

● (2035)

Mr. Michael Barrett: Right. I think I have 30 seconds left, Dr. Herx. Thank you for your responses.

Do you have any thoughts on the regional variation of MAID rates, with a very high number—the highest in the world—coming from Victoria, B.C., and does this cause you concern?

Dr. Leonie Herx: It's very alarming. I think that if there is an area where any medical procedure is being done at much higher rates than anywhere else in a country or in a program, it should be put under significant scrutiny and reviewed to find out what is happening there that's so awry with the rest of the country. I would hope that an assessment of the situation on Vancouver Island is going to be happening.

Mr. Michael Barrett: Yes. Thanks very much, Dr. Herx.

Thank you, Madam Co-Chair.

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

The next person will be Dr. Fry, for five minutes.

Hon. Hedy Fry (Vancouver Centre, Lib.): Thank you very much. I want to thank everyone for coming today and giving us their time on a very complex issue.

I'm a family physician, or I used to be family physician, for very many years, and I find that what I'm hearing today is people suggesting that it is one thing or the other, that you either seek MAID or you seek palliative care, and I don't think that's true.

I really do, in terms of my own experience with patients, feel that palliative care has a place. A lot of people wish for palliative care, and then after that, they may get to a point where they decide that whatever is going on with their lives is unbearable and that they want to access MAID.

You have questioned Ms. Hoffman's and Health Canada's report that 82.8% of people who accessed MAID had palliative care given to them. I think the "either/or" concerns me a little bit, the idea that there is one silver bullet that if accessed by everyone would enable them to get better.

I think Dr. Naud said it extremely well. I almost got up and applauded when he said that assessing or giving a patient MAID or palliative care, or whatever else you may do to give them support, is about the patient. It's not about whether the physician believes that their decision is the most important decision for the patient; it's about knowing and assessing your patient and knowing when your patient has come to the point where they can trust you to tell you, “You know what? This has been working well. I am feeling very good about myself, but I really don't want to do it any more. I've just had it, with my years, etc.” I think it's really important for us to start talking about the things that happen if a patient who is in palliative care says, “I would like to have access to MAID.” What is it that you would say to that patient, Dr. Herx?

I know that Dr. Naud talks about the patient and the patient's limits, the patient's tolerance. It is, at the end of the day, about the patient. I think the issue of advance directives is something I'd like to get into, but I don't think I'm going to have time.

How do you make a decision in the best interest of your patient, Dr. Naud, when your patient is going through the end of life, when they're going through pain and so on? How do you make those decisions on an individual case-by-case basis?

The Joint Chair (Hon. Yonah Martin): First we'll go to Dr. Herx, followed by Dr. Naud.

Hon. Hedy Fry: No, I would prefer that Dr. Naud answer the question.

[*Translation*]

Dr. Alain Naud: Thank you very much for the question, which is indeed important.

Opponents of medical assistance in dying have long tried to portray medical assistance in dying and palliative care as mutually exclusive. That is the tactic that says you are with someone or against them. In fact, they are not in conflict. As I said, they are complementary and interrelated forms of care.

In Quebec, when the Act respecting end of life care was enacted and medical assistance in dying began to be offered, all public health institutions in Quebec had an obligation to offer this end of life care to all Quebeckers and to make it available.

The idea is not to impose medical assistance in dying, but to make it available. The only exception was for hospices, which are autonomous institutions managed by their own boards of administration. Originally, in December 2015, all these institutions had said they would never offer medical assistance in dying, because it was contrary to palliative care.

Determining for a patient what is the best way to die, for them, smacks of a medical paternalism that has no place in 2022. As caregivers, as physicians, our role is to inform the patient of the options available to them, make sure they clearly understand, and respect their choice, regardless of our own choice, our own values and our own convictions.

In end of life situations, there aren't 50 options, there are four: palliative care, medical assistance in dying, palliative sedation, and refusing or stopping treatment.

I'll come back to the 34 hospices—there are now many more than that in Quebec—that refused to offer medical assistance in dying. Today, more than half of them also offer medical assistance in dying in the care they provide.

We are focused on what the public requests and the interests of patients. One fact has always been true: among the patients who entered hospices, many requested medical assistance in dying along the way, because they could not suffer any longer. All that they could be offered was to put them to sleep until they died. That is not what people wanted.

● (2040)

[*English*]

The Joint Chair (Hon. Yonah Martin): There are actually less than 10 seconds.

Hon. Hedy Fry: My goodness, I just wanted to ask Dr. Herx something. She is making a point that there must be more palliative care available to people.

I do agree with Dr. Naud, because I think it is paternalistic to tell a patient at the end of the time when that patient makes a decision what is best for the patient or not.

The Joint Chair (Hon. Yonah Martin): Okay, thank you, Dr. Fry.

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

[*Translation*]

Mr. Luc Thériault: Thank you, Madam Chair.

Dr. Naud, you are entirely right to talk about experience in Quebec, which has included in a continuum of care the possibility that a request for medical assistance in dying will emerge along the way, rather than treating it as conflicting with other care.

Dr. Herx said that we had to take a holistic approach, and I absolutely agree. However, how would palliative care, this comprehensive support in dying, suddenly create a feeling of failure if one fine day, because the dying person has received good palliative care, they are completely calm and say they are ready to let go? It might also be a success for palliative care, to allow for genuine support in dying, might it not?

Dr. Alain Naud: You are entirely correct. We must certainly not see it as a failure, but as an element in a continuum of care, quite simply.

Again, medical assistance in dying is a legitimate and legal type of care; it is not a shameful type of care. I have been involved in palliative care for 37 years and in medical assistance in dying since the beginning, and I have never promoted medical assistance in dying. In my opinion, that care is no more or less honourable than palliative care, sedation or refusing treatment. What is important is to offer the patient the options that are available, explain them clearly, and make sure the patient is making the decision based on their own values, beliefs and convictions.

In the field of palliative care, some of the opponents of medical assistance in dying oppose it based on religions conviction, which is often carefully concealed, and some out of ideological conviction. We could so a whole psychoanalytic examination of this. We know how important palliative care is and how significant a role it has played in the last 30 years. It was essential to be able to offer it to all Quebeckers. So I think that some physicians see medical assistance in dying as an admission of failure. They may unconsciously feel that they have failed when they find themselves in a situation where they have promised to support a patient until their death and they have to tell the patient that they can no longer support them at their end of life because the patient has made a choice they oppose.

Personally, as a palliative care physician, when I get a request from a patient who tells me that the oncologist says there is nothing left to be done, I tell them that there is everything left to be done, that we will do it together and I will hold their hand to the end, regardless of what end of life choice they make. I tell them I will be with them and I will respect their choice.

[*English*]

Dr. Leonie Herx: Yes, I would just say that unfortunately not everyone in Canada has access to palliative care, and you mentioned that everyone in Quebec should have access as well. It is not available. I explained the statistics of only 30%-50% of patients having access to palliative care, and they don't have it early enough in their disease trajectory to make a difference in reducing irremediable suffering. It's not about whether MAID is right or wrong; it's that people do not have access to palliative care. Then they have unnecessary suffering that leads to MAID requests, and this is something that can lead to wrongful death, and that's not okay.

[*Translation*]

Mr. Luc Thériault: So again you have a mindset that sees them as being in conflict. Essentially, in your opinion, if someone requests medical assistance in dying, it's because they haven't received good palliative care, and palliative care is the only solution for dying with dignity. We understand.

Dr. Naud, the committee will have to decide whether or not to recommend a change to the Criminal Code to expand access to medical assistance in dying. However, before authorizing it for persons with dementia, for example, Parliament would have to be satisfied that it is possible to establish guidelines to ensure that the patient's freedom of choice is respected.

Could you talk to us about these guidelines?

● (2045)

Dr. Alain Naud: Thank you for the question.

In my brief, I propose very clear guidelines, that have an objective basis and adhere to the principle of self-determination and the choice made by the patient when they are still competent to make it. I can describe the process, very briefly. After meeting with their physician, the patient would give the physician a signed request form. In the request, which would have to be renewed after a certain period of time, the patient would determine, in their own judgment, the objective criteria stating the point at which, having become incompetent, they would be in a state of indignity. The patient should also designate a third party whose mandate would be, not to determine that the time had come, but to call on the treatment team, quite simply, to have them do the assessment to see whether the time, as predefined by the patient, had come. I think that is something we are capable of putting in place very easily.

[*English*]

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

Next we have Mr. MacGregor for five minutes.

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

Dr. Herx, maybe I'll start with you. I was a member of Parliament in the 42nd Parliament when the original debate on Bill C-14 was going on in 2016. I remember the very passionate debates in the House during that time. Opinions voiced by members spanned the entire spectrum. Concurrently with that debate, there was also an acknowledgement that we as a country needed to do better in terms of giving patients palliative care options. In my own community in the Cowichan Valley on Vancouver Island, Cowichan Hospice has benefited tremendously from the building of a new palliative care centre, which has expanded the number of beds that are available.

I want to take a little walk down memory lane with you over the last number of years.

The original Bill C-14 was passed in 2016. We had all-party support in 2017 for the palliative care framework. Dr. Herx, when you saw that renewed focus on palliative care in Canada that came first in 2016 with the debate on Bill C-14 and then with the passing of the palliative care framework, did you see an improvement in 2017, 2018, and 2019, and then did it just ebb? Have we just lost the plot a bit, and do we need to refocus the attention a bit? I want to get a sense from you of what those previous years were like.

Dr. Leonie Herx: Certainly there is renewed attention, as you said, on the importance of palliative care, and it was indeed positioned, by both the Supreme Court and in the Bill C-14 legislation, as something that could alleviate suffering that might lead to a request for hastened death. We were so fortunate to have supported, through the Canadian Society of Palliative Care Physicians, Bill C-277, which created the national framework for palliative care. What that really allowed us to do was to put together all the good work that's been done across the country, informed by international standards, to solidify what we need to achieve in Canada to make palliative care a reality.

Unfortunately, we haven't really done anything further than to put a framework on paper. What we need is the money and the infrastructure to get the boots on the ground. We now have clearly defined national competencies for all professionals who provide a palliative approach to care for their patients and for the specialist training that is needed, but they are not embedded into curricula across the country. We do not have quality standards to evaluate what palliative care is happening across the country. That goes back to the Health Canada data. We just don't know what's happening and who's providing the care, although now we have these credentialing programs.

We need a national system that's linked to Accreditation Canada's standards and that's administered so that provinces collect data on outcomes for patients that is patient-reported. We also need the quality standards to make sure that provinces are accountable for improving both the quality of palliative care and the access to it. Achieving that will take a sustained investment of resources over time to get those trainings embedded, to get the standards up and to hold the provinces accountable through accreditation standards. That's absolutely needed, and we haven't seen any of that. There was no money in the last federal budget, and that needs to change. At least 95% of Canadians don't want to die via an assisted death, so let's put some money into supporting the needs of all those people who don't want MAID.

● (2050)

Mr. Alistair MacGregor: Yes, that's a fair point. I think we will struggle as policy-makers to always try to respect the agency of the patient. We want them to have the best available care so they can make the best decisions for themselves.

Maybe, Dr. Naud, I can get you to chime in on the same theme. When you look back over the last number of years, since 2016 and 2017, do you have any thoughts on how the national intention regarding palliative care has ebbed and flowed and what more needs to be done?

[*Translation*]

Dr. Alain Naud: We are all in agreement that palliative care must be offered everywhere and to everyone who needs it. No one is opposed to that.

In my position, here in Quebec City, I hear the argument that medical assistance in dying has resulted in a reduction in funding allocated to palliative care. But I have never seen any proof of that. I am still waiting for the evidence, very simply. I think that palliative care is underfunded in general, and has been for a very long time. That has nothing to do with the advent of medical assistance in dying.

Again, we have to stop looking at the possibility of receiving medical assistance in dying as something that is the opposite of quality palliative care. We need to have both and respect the patient's free and informed choice. It comes down to the principle of self-determination again.

[*English*]

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

Mr. Co-Chair, I will turn it back to you for the senators' questions.

[*Translation*]

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

We will now move on to the senators, starting again with Senator Mégie.

Senator Mégie, you have the floor for three minutes.

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

My question is for Dr. Naud.

What would your answer be to the argument we often hear, that there would be fewer requests for medical assistance in dying if there were better palliative care?

Dr. Alain Naud: Thank you for the question, senator.

This was an argument used by opponents of medical assistance in dying. In Quebec, we started talking about medical assistance in dying in 2009, when the government set up the Select Committee on Dying with Dignity, and continued until the Act respecting end-of-life care was enacted in June 2014. It is an argument we heard constantly. But we knew it was wrong, and our experience for almost six and a half years has shown it to have been wrong. No patient receives medical assistance in dying because they don't have access to quality palliative care.

In Quebec, we compile excellent statistics on this, unlike some other places in Canada. The Commission sur les soins de fin de vie, which was established under Quebec's Act respecting end-of-life care, compiles rigorous statistics. As I said in my presentation, 80 per cent of patients in Quebec who receive medical assistance in dying were already receiving palliative care; the others, who represent 20 per cent, voluntarily declined to receive palliative care. When we meet with a patient who is requesting medical assistance in dying, we have an obligation to talk to them about treatment and pain relief possibilities still available to them. We have an obligation to talk to them about the possibility of getting palliative care if they have not already had it. Nonetheless, 20 per cent of people who receive medical assistance in dying voluntarily declined to receive palliative care.

I also talked about the experience of hospices, which initially refused to offer medical assistance in dying. That didn't mean that there were no requests in all those facilities. When those patients were two or three days from death and were in horrendous condition, they were transferred to a hospital so they could receive medical assistance in dying. Now, more than half of those hospices offer medical assistance in dying without providing any worse palliative care. It is a matter of time. When Quebec's Act respecting end-of-life care is amended, I am sure that the exemption enjoyed by hospices will be removed.

So that argument is wrong, and we can prove it and provide the evidence that the argument was wrong from the start.

● (2055)

Hon. Marie-Françoise Mégie: Do I have time to ask another question?

The Joint Chair (Hon. Marc Garneau): You have 30 seconds left.

Hon. Marie-Françoise Mégie: In your brief, Dr. Naud, you propose protective measures in the event that medical assistance in dying were expanded to mature minors and persons whose only diagnosis is a mental health problem. Do you foresee safeguarding measures?

Dr. Alain Naud: Certainly, senator. In my brief, I refer to the position taken by the Collège des médecins du Québec, the experience of Belgium and the Netherlands, and the reports of experts in psychiatry who are proposing measures. I am thinking of the Association des médecins psychiatres du Québec, which has produced a voluminous document talking about the measures to be put in place, among others. I think the experts have to be involved in this.

On the question of minors, in the Netherlands and Belgium, for example, in addition to the two physicians, there is a requirement to have an opinion from a pediatric psychiatrist or a psychiatrist on the minor's maturity. You have to understand that adolescents aged 14 to 18 years are not immature. On the contrary, these young people, who have been very sick, are often possessed of a maturity that most young people their age do not have. It is therefore wrong to think that because they are under 18, they are not competent to consent to medical assistance in dying. As physicians or specialists, we are capable of properly assessing that competence to consent to medical assistance in dying.

These are in fact clienteles for whom we have to have additional safeguarding measures, in addition to those we already have.

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

[*English*]

Senator Kutcher, you have three minutes.

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

I have three short questions for Dr. Herx.

What proportion of Canadian palliative care physicians currently also provide MAID?

Dr. Leonie Herx: Thank you for the question.

We don't have any recent statistics on that, Senator Kutcher. Our most recent survey from the Canadian Society of Palliative Care Physicians shows that 92% of palliative care physicians did not provide MAID, but we haven't resurveyed recently.

Hon. Stanley Kutcher: Thank you.

When MAID became available in Canada, was there a consensus among palliative care physicians that MAID should be provided?

Dr. Leonie Herx: Sorry; what do you mean by “should be provided”?

Hon. Stanley Kutcher: If people wanted MAID instead of palliative care, was there consensus among palliative care physicians that it should happen?

Dr. Leonie Herx: The consensus among palliative care physicians was that hastening death and ending someone's life is not part of the practice of palliative care.

Certainly there are some individual palliative care clinicians who choose to make MAID part of their medical practice, as you can in any specialty—you can build a MAID practice—but it was very clear and consistent in the palliative care community that MAID is not part of the philosophy of palliative care.

Hon. Stanley Kutcher: So it would be correct to say that there was no consensus.

Dr. Leonie Herx: No, we did not discuss anything to do with whether MAID was right or wrong. We don't make legal decisions. As medical professionals, we discuss what is a competency within our medical discipline, and ending someone's life is not part of that.

Hon. Stanley Kutcher: So there was no consensus that ending someone's life was part of what you were doing.

Dr. Leonie Herx: No, there was consensus that ending life is not part of palliative care and not part of the skill set of a palliative care clinician.

Hon. Stanley Kutcher: I hear you. I was just saying it the other way around.

Is there consensus now among palliative care physicians that track two MAID, as described in Bill C-7, should be provided by palliative care physicians?

Dr. Leonie Herx: We have not surveyed our clinicians. Those aren't typically the patients we're involved in caring for. We usually provide care for patients who meet the reasonably foreseeable death criterion.

Hon. Stanley Kutcher: So you would not have information on whether or not palliative care physicians, as a group, are in favour or not in favour.

Dr. Leonie Herx: We would not have that information.

Hon. Stanley Kutcher: What would be the hypothesis?

Dr. Leonie Herx: I think the point is that this is not about whether or not people are in favour of MAID; this is about how people can access the care they need to live. Currently in Canada, we don't have the infrastructure for people to have palliative care.

Hon. Stanley Kutcher: I don't think people are debating that. We all agree on that. The issue I'm trying to understand is whether there is consensus within the community of palliative care physicians that track two MAID should be provided.

Dr. Leonie Herx: Certainly the Canadian Society of Palliative Care Physicians and the Canadian Hospice Palliative Care Association spoke out against Bill C-7 and thought it was putting too many vulnerable lives at risk, so I would say that the consensus of the two national organizations is that it was wrong to extend MAID to track two.

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

We'll now go to Senator Dalphond.

[*Translation*]

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

My question is for Dr. Naud.

You may have heard the testimony of Dr. Pageau, in the previous group of witnesses, who seems to make a distinction between not preventing death from happening—which is how he sees advance medical directives—and causing death—which is how he sees advance requests for access to medical assistance in dying.

I understand the distinction from a legal standpoint, but from the standpoint of medical ethics, does that really present a problem, Dr. Naud?

● (2100)

Dr. Alain Naud: Thank you, senator.

There is no problem in that regard. The only problem lies with the caregiver themself. You know that opponents of medical assistance in dying use the term "euthanasia" a lot, with contempt, saying that this is euthanasia. We have to go back to the Greek root of the word "euthanasia" to understand that the word means "a beautiful death". In Belgium, there is no hesitation about using this word, which in fact is part of the name of the federal commission to oversee and evaluate the law on euthanasia.

Medical assistance in dying is an act of euthanasia. It is medical care that consists of relieving suffering. What is the best way of relieving suffering? As a caregiver, it is not up to us to determine it. When it is a matter of end of life dignity and the best way to die, I don't have the answer. It is not for me to choose or decide for a patient. Again, my role as caregiver is to explain to the patient the options available to them and completely respect their choice.

Surveys show that 85 to 90 per cent of the general public support medical assistance in dying. The proportion is even slightly higher among physicians in Quebec, according to a survey done by the Collège des médecins du Québec on the question. So that means that 10 to 15 per cent of the public oppose medical assistance in dying. Certainly, if you ask the people who have opposed medical assistance in dying since the start whether they support expanding access, their answer will be no. That proportion of the public will always oppose expanding access to medical assistance in dying.

Personally, I think we have to respect the wishes of the majority of the population of Canada and Quebec and know exactly what an expansion of access to medical assistance in dying will look like. We can debate death, end of life dignity and the best way to die at length. In my opinion, it is up to each individual to determine what the best way to die is.

Some people will say that God is the one who gave them life and it is up to him to take it back. As a palliative care physician, I completely respect that position. Those people want to experience a terminal coma or terminal agony phase. I think we have all seen this kind of situation in our families, where the person is going to die gasping for breath, mouth open, for 10 days. On the other hand, some people absolutely do not envision their end of life like that, because they have seen their parent die that way and they say to themselves that their own life is not going to end like that.

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

[*English*]

We'll now proceed with Senator Wallin for three minutes.

Hon. Pamela Wallin: Thank you very much.

I have a question for Leonie Herx.

MAID is the law of the land. You understand that, correct?

Dr. Leonie Herx: This is not about MAID being right or wrong. This is about access to care that relieves suffering before it becomes irremediable.

Hon. Pamela Wallin: You have said, in answer to one of my colleague's questions, that you've not really surveyed your clinicians on the question of MAID specifically, and whether they would offer it. You said no palliative care clinician would want to do that. Are you saying that palliative care clinicians, if asked by a patient to discuss MAID or to have someone come in and hear their request for it or to explain the options, would refuse to do so?

Dr. Leonie Herx: My goodness, absolutely not. I'm not sure where that idea came from. We provide our patients with all of the information so that they can make a choice that's best for them.

We have a special expertise that comes through our certified training program. Palliative care has come so far in the past 10 to 15 years in terms of its advances to understand symptoms, especially spiritual and psychological distress. We accompany people. We have a specific expertise to support people in focusing on living and reframing hope. We're not there to hasten someone's death. That doesn't mean that a person can't access MAID.

Hon. Pamela Wallin: No, I'm not talking about hastening their death. If they say, “I've been through the palliative process. I personally see this as a continuum. I would like to go to the next step now and choose MAID”, what do you do? Do you bring in someone who will discuss this? Do you give them access?

● (2105)

Dr. Leonie Herx: Us? No. We discuss all options with our patients.

Hon. Pamela Wallin: How do you do that?

Dr. Leonie Herx: I can't go into specific examples, but we make sure patients have all the understanding they need, which includes understanding palliative care. One of the biggest—

Hon. Pamela Wallin: I'm not talking about palliative care.

Dr. Leonie Herx: It's actually part of—

Hon. Pamela Wallin: I know you do that.

Dr. Leonie Herx: I'm speaking about how I would respond.

Hon. Pamela Wallin: I'm talking about a patient saying, “Okay, I am coming to the end of my willingness to pursue palliative care, and now I'd like to discuss MAID.”

Dr. Leonie Herx: I would like to answer the question.

Hon. Pamela Wallin: This is the question. When patients choose MAID at this point, what do you do?

Dr. Leonie Herx: I will first make sure to know what is going on with the patients and what they understood about palliative care. That is crucial. Palliative care is so misunderstood by people, and people don't understand what natural dying and death look like.

I am saying that's part of how we respond.

Hon. Pamela Wallin: I'm not asking that question. My time is very short.

I would like to know what it is that you do when a patient says that. What do you do? Do you call a local MAID provider?

Dr. Leonie Herx: That's what I'm trying to explain.

I'm explaining that first we explore the whole question with the patients and ensure they understand all the options, including palliative care. They may have misconceptions, because palliative care is very stigmatized.

Hon. Pamela Wallin: No, if they're going through palliative, they've understood that. Now they've come to a new conclusion.

The Joint Chair (Hon. Marc Garneau): Thank you. We're going to have to end this round.

Senator Martin, we'll go over to you for three minutes.

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

I've asked several other witnesses, and I just want to be clear. We have MAID and we have palliative care as part of a spectrum of care. In British Columbia, I've heard from some witnesses that there is a lack of funding, or less funding, for palliative care because there seems to be a certain competition. I don't have a better word for it.

Would you speak to any examples, such as the one we have seen in B.C.? The Delta Hospice Society is one example. Has there been less funding available for palliative care, even though we have this national framework?

Dr. Leonie Herx: Thank you, Senator Martin.

Unfortunately—and that was an add-on to the question Mr. MacGregor asked me earlier—while we haven't seen new investments in palliative care in terms of improving accessibility and being able to measure the quality of palliative care that's being referred to in the Health Canada reports, we have seen a loss of palliative care resources.

As I referred to in my brief remarks, and there are further details in my written brief, existing palliative care resources have been used to provide MAID. Palliative care funding in different provinces is being used to fund MAID programs, so we have less access to palliative care than we had before MAID was legalized.

We have clinicians who are now being asked to provide MAID. Lots of hospice palliative care nurses have now left their jobs because they are so demoralized by being unable to provide the palliative care that they went into their job for. It's been lumped into budgets with palliative and end-of-life care, and MAID is being funded out of existing palliative care dollars.

It is compromising already scarce resources for palliative care and, as I mentioned, some hospices have been forced to admit people just to provide the procedure of MAID, not to provide holistic palliative care. They are using this scarce palliative care resource, at the cost of other people who want palliative care and a natural death not being able to access it. We have had devastating impacts on palliative care in the last few years.

The Joint Chair (Hon. Yonah Martin): I wonder if I can use my remaining time for you to finish your answer to my colleague, Senator Wallin, about what your response would be to a patient in palliative care who wished to access MAID.

Dr. Leonie Herx: First and foremost, our expertise is in addressing suffering, so we come alongside a person to understand what's going on in their unique context. Not all requests for MAID are from somebody who wants to immediately terminate their life. Often requests for a desire for death in MAID come from suffering that needs to be heard, and lament and grief that are a normal part of coming to terms with the possibility of your own death.

We have all kinds of interventions and supports that can help reframe living for people, and people want to live. Our first responsibility is to help make sure what it is a person is actually asking for and that they understand all the things that are available to them. Absolutely, we talk to them about the procedure of MAID and what it is, and if that's what they want, we make sure that they have access to it.

That is not precluded from.... They are not separate in the sense that they can't have MAID if they have palliative care. I want to be clear on that. We provide palliative care to everyone regardless, but MAID is not part of palliative care. It is a separate medical procedure and it shouldn't be provided through existing palliative care resources or in the context of palliative care.

● (2110)

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

This brings the second panel to—

Mr. James Maloney: Mr. Chair, I have a quick point of order.

The Joint Chair (Hon. Marc Garneau): Yes, Mr. Maloney, go ahead.

Mr. James Maloney: I'm not sure it's a point of order, but I haven't had the benefit of seeing Dr. Herx's paper and I'm not sure anybody else has either. Perhaps that's because it hasn't been translated.

To the extent that the data she referred to is not in her paper, with respect to people leaving the industry and MAID detracting from the resources available to the palliative care sector, I wonder if she could provide that information to us in writing.

The Joint Chair (Hon. Marc Garneau): Would you like to respond, Dr. Herx?

Dr. Leonie Herx: Yes, thank you. It's all in my brief. I'm sorry; I submitted it in English only. It is with the clerk of the committee.

The Joint Chair (Hon. Marc Garneau): Very good. Thank you very much, Dr. Herx.

[*Translation*]

Thank you very much for your testimony this evening, Dr. Naud.

[*English*]

We very much appreciate hearing from you and your answering our questions.

We will now suspend in preparation for panel number three.

Thank you. Good evening.

● (2110)

_____________________(Pause)_____________________

● (2110)

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

We're going to start panel number 3. I don't see my co-chair—oh, I see her now.

Senator Martin, it's over to you.

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

We will have three witnesses for this third panel. If I can, I will make a few comments about what will happen.

Before speaking, please wait until one of the co-chairs recognizes you by name. I would remind you that all comments should be addressed through the joint chairs.

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

With that, I'd like to welcome our witnesses for the third panel. As an individual, we have Audrey Baylis, who is a retired registered nurse. We have Diane Reva Gwartz, nurse practitioner in primary health care, and Dr. Sonu Gaind, who is a professor.

Thank you all for joining us. We will begin with opening remarks for five minutes each. First we'll have Ms. Baylis, then Ms. Gwartz, and then Dr. Gaind.

Ms. Baylis, the floor is yours.

● (2115)

Ms. Audrey Baylis (Retired Registered Nurse, As an Individual): Thank you, Madam Chair and committee members.

The reason I requested to be a witness before this committee is twofold. The first part is to have legislation changed to be able to preplan the end of life while still a healthy individual—for example, when you make your will—and to be able to make a choice. The second part would be education, as I believe that attitudes do not change without education.

My husband had MAID on November 23, 2020.

He had a double bypass in 2000 and a pacemaker/defibrillator installed in 2009. He had a good quality of life until 2019, when his condition began to worsen. In the spring of 2020, his family doctor advised him that there was no further treatment available to improve his quality of life. The doctor, who was very proactive, discussed what to expect for quality of life until his end of life and described his choices: palliative care or MAID. For the next six months, we travelled Ontario, visiting relatives and friends.

As his condition worsened, he sought MAID. A date was set for November 29, his birthday; however, his condition got severely worse, and on November 23, he had MAID. The family all came on the morning of the event, and we have nothing but good memories, because he was there for all the conversations, and he said goodbye.

When the doctor came, she asked if he was ready. Lester gave a hug and said he loved them. He went into the bedroom and lay on the bed. I lay beside him and held his hand, and he said goodbye. The doctor asked him again if this was what he wanted, and he responded, “Yes.” What better way to end a life? We have only good memories.

The reason that I am so passionate about preplanning is that prior to the age of 31, I had three cardiac arrests and had two-thirds of my stomach surgically removed. I had three children and worked full time, so I did worry about my future, and 50-plus years ago, I put a plan in place for my end of life. I have a document signed by my family and friends for them to take me to Switzerland for medically assisted death. The document clearly states my wishes and the criteria for my family to make that decision.

To conclude, the need for preplanning is to ensure you have a choice on how you would want to proceed with your end of life, beyond religion and external influences, prior to a medical event or accident that later will make you incompetent to make that choice.

On the second part, education, I recommend a federal-provincial initiative to add to the curriculum in all medical teaching institutions the “last phase of life up to end of life”, emphasizing the need for the patient to be part of all medical discussions. This mould of talking to the family, not the patient, needs to be broken.

I would like to see this done in three parts. First, in the “last phase of life to end of life” section, the doctor states that he or she has no further treatment to offer to the patient to enhance their quality of life and discusses with the patient what they could expect as their condition worsens up to the end of life, and what their choices are. The second part is palliative care and MAID; these should be taught in depth. Number three is continuing education.

Here's my final thought. I personally find it hard to understand the negativity around MAID, as in both scenarios you will die of a drug unless you die of a coronary. Palliative care is a longer process in which you are well cared for and kept comfortable with a drug until your body shuts down, most of the time as a result of the same drug. In MAID, you choose your date and have your family with you, and you are still part of all the conversations up until you say goodbye.

I would like to thank Mr. Longpre for his assistance over the last few months, and Adam Moore for recommending me.

● (2120)

Thank you. I'm very willing to answer questions.

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

Next we'll go to Diane Reva Gwartz for five minutes.

Ms. Diane Reva Gwartz (Nurse Practitioner, Primary Health Care, As an Individual): Thank you for this opportunity to present to your committee.

I have been a nurse practitioner for over 20 years and a MAID assessor and provider since June of 2018. At the time that I became involved with MAID, there were no community providers in Niagara, where I live and work, and no funding mechanism for NPs to provide this care. As such, I worked as a MAID practitioner without any financial compensation for almost three years, until specific funding was established one year ago.

To date, I have completed 55 MAID assessments and 24 provisions, and I am an active member of the Canadian Association of MAiD Assessors and Providers.

In addition, I think it is relevant to this committee that I am also a family member of a recipient of MAID, as my mother—who had both serious physical health problems and a long-standing mental illness—had an assisted death in August of 2018.

I was asked to present today on the implementation of MAID in Canada. I am going to speak to what I think have been the major successes and challenges, as well as recommendations that I have for moving forward.

First, I credit Canada for establishing assisted death as a universal health care option for all citizens who meet the eligibility criteria, and for the focus of care being centred on patient needs and desires.

In addition, I believe that the changes in legislation with Bill C-7 in March of 2021 have improved the process of MAID, specifically with the elimination of the reflection period, the introduction of the waiver of final consent and the opportunity to access MAID for those whose death is not reasonably foreseeable.

As a MAID practitioner, I consider it a privilege to be able to provide this care to those who are suffering intolerably, but it is also the most emotionally challenging work of my nursing career. With increasing numbers of MAID requests and the significant workload demands related to the assessment of patients who do not have a reasonably foreseeable death, the dearth of MAID practitioners is a serious challenge to care provision.

With anticipation of the passing of legislation to allow for mental illness as the sole underlying medical condition, this workload will undoubtedly increase dramatically. Across Canada there are nurse practitioners who are interested in providing MAID care but require a funding mechanism in order to do so. This country’s network of MAID practitioners is an amazing resource that needs to be protected and expanded to allow for the availability of MAID as an aspect of end-of-life care to all Canadians.

Unfortunately, in many communities institutional policies prevent the provision of MAID to those requesting it. For example, in my community, due to hospital policies and resources, it is difficult to receive MAID in the hospital system. The rehabilitation centre and hospice both have policies that specifically prohibit the provision of MAID in their centres. It is inequitable and unjust that individual institutions are able to establish policies that deprive those who require their services the opportunity to access an assisted death.

The final challenges I'd like to address are limited awareness, community supports and access to assisted dying services.

There are many communities, like my own, where the awareness of MAID as an end-of-life option is very limited and not well communicated to patients and families. In addition, support services for MAID are extremely limited. As community providers, we need assistance from the health care system for management of referrals, administrative support and community liaison activities. Lastly, inequitable access to MAID care, geographically, is a significant challenge in this country.

Finally, here are my recommendations.

As I'm sure you are aware, there is significant interest in the concept of advance requests for assisted dying. This would allow for patients who are preparing for a decline in health status and capacity—for example, those with dementia or neurological conditions—to specify criteria and/or conditions that would then trigger their MAID request. Currently, patients often feel caught between choosing to have MAID before they are actually ready and missing the opportunity to access MAID due to loss of capacity.

The need for enhanced resources for MAID practitioners is already a significant issue. However, with the potential changes as of March 2023, planning for health care resources is critical. Adequate funding to ensure MAID practitioners are able to provide this care, as well as to support training of new practitioners, is fundamental in anticipation of the increased demand and time commitments that the assessment process will require for those with mental illness as their main condition.

In addition, a plan is needed to ensure that there will be the necessary psychiatric resources in place to support this work. It is essential that planning to ensure adequate funding and supports occurs prior to the implementation of legislative changes.

● (2125)

Lastly, those of us providing MAID care in the community desperately need support. There needs to be increased funding for those who provide MAID in the community, including nurse practitioners, and an organizational infrastructure to support the work that we do. This will ensure that MAID care is available for those who wish to die peacefully in their own homes, at their request and surrounded by those who mean the most to them.

I appreciate having had this opportunity to present to your committee and to share my thoughts on the implementation of medical assistance in dying in Canada. I look forward to your questions.

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

Lastly, we have Dr. Sonu Gaind.

Dr. K. Sonu Gaind (Professor, As an Individual): Thank you, Madam Chair, for the chance to speak.

My name is Sonu Gaind. I'm a professor at the University of Toronto and chief of psychiatry at Humber River Hospital, where I serve a diverse population, including marginalized communities. I'm a former president of both the Canadian Psychiatric Association and the Ontario Psychiatric Association and I sat on the Council of Canadian Academies panel on mental illness. I've worked in psycho-oncology with dying patients and their families throughout my career.

I'm speaking as an individual; I'm not representing any group I work with.

I'm also physician chair of my hospital's MAID team and not a conscientious objector. I don't bring any particular ideology to the issue other than advocating for evidence. I believe sensitive public policies like this demand a non-ideological, evidence-based approach. I've seen the benefits of MAID in appropriate situations like Mr. Baylis'. I have also been sensitized to the dangers of MAID in inappropriate points. I've come to realize that our MAID expansion to non-dying disabled and those suffering from solely mental illness is a tale of two cities—of two worlds, actually.

Evidence shows that when death is foreseeable, people seek MAID to preserve dignity and autonomy to avoid a painful death. Those seeking MAID in these situations tend to be, in researchers' words, white, more educated and more privileged. That's been used to suggest that MAID is safe to expand to other situations.

However, when expanded to the non-dying disabled for mental illness, that association completely flips. A different group gets MAID. These are the group of non-dying marginalized, who have never had autonomy to live a life with dignity. Rather that death with dignity, they are seeking an escape from life's suffering. They do overlap with those who are suicidal in the traditional sense.

Evidence shows that this group is more marginalized and has unresolved psychosocial suffering, such as loneliness and isolation. A terrifying gender gap emerges of twice as many women as men receiving death to avoid life suffering.

Introduced to help avoid painful deaths, MAID expansion provides these marginalized, non-dying people with death to escape painful lives. Worse, many of these people could have gotten better. CAMH, the Canadian Association for Suicide Prevention and others have concluded that evidence shows we cannot predict irremediability of mental illness in any individual.

I can't comment on the federal mental illness panel's specific recommendations, since their report is delayed. Still, the panel cannot manufacture non-existent evidence. That panel was charged with recommending protocols, guidance and safeguards on how to implement MAID for mental illness, not with reviewing whether that can safely be done.

That and the sunset clause is not how science works. No drug company is told their sleeping pill will be approved in two years without evidence of effectiveness or safety while being asked to develop instructions in the meantime on how to use the pill. The sunset clause and the federal panel's mandate are based on less evidence than is required for introducing any sleeping pill.

In bypassing the primary safeguard against premature death, which is getting MAID only when we can predict irremediability, any other so-called safeguards can be no more than false reassurances and lip service. Marginalized people in despair who could get better will get MAID. I think it bodes ill that a member of the 12-person panel resigned months ago, though her name remains on the public website.

While over 85% of Ontario psychiatrists who responded in a recent survey supported MAID in general, less than 30% agree with MAID for solely mental illness. They opposed the sunset clause by a 3:1 margin. The Quebec commission has now recommended against providing MAID for sole mental illness.

Last March in the House, Monsieur Thériault said, “If the expert panel and special committee arrive at the conclusion that mental health should be excluded, it will be excluded.” The panel's narrow charge would have prevented them even considering excluding mental health. I call on you now to listen to the evidence and honour that commitment through this special committee.

I grew up hearing the story of the *Komagata Maru* and about those who were refused entry to Canada and sent back to India, some to their deaths. As a child, it showed me that the policy, the continuous passage act, could ostensibly be the same for everyone, yet in actuality be racist towards some. I view our current MAID expansion the same way. That's the tale of two worlds. It's the same law, but with different impacts on different groups.

It's a myth that expanded MAID is just about autonomy. The planned expansion and sunset clause may increase privileged autonomy for some to die with dignity, but it will do so by sacrificing other marginalized Canadians to premature deaths for escaping painful lives that society failed to allow them to live with dignity. That's not my Canada, and it should not be yours.

Thank you for listening. I'd be happy to answer any questions.

● (2130)

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

Thank you to all of our witnesses for their compelling testimonies.

We'll begin our first round with Madame Vien for five minutes.

[*Translation*]

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

My first question is for Ms. Gwartz. Ms. Baylis can also give us her view.

Ms. Gwartz, did you hear the testimony of Dr. Félix Pageau earlier?

[*English*]

Mrs. Diane Reva Gwartz: I apologize. I was not aware that I was allowed to be in.

[*Translation*]

Mrs. Dominique Vien: So you didn't hear it.

[*English*]

Mrs. Diane Reva Gwartz: No.

[*Translation*]

Mrs. Dominique Vien: Dr. Pageau maintained that a person with dementia should not have access to medical assistance in dying, even if they had made an advance request for it. He said that such access would be unethical, because, in another context, that person would not necessarily make the same decision. In his opinion, this was therefore a contradiction. The two don't go together, they don't go hand in hand.

What do you think about that position, Ms. Gwartz?

[*English*]

Mrs. Diane Reva Gwartz: It's a difficult question. I don't know all of the safeguards that would be put into place in order for advance requests to be incorporated into the legislation for MAID.

I believe, in terms of respecting autonomy and trying to minimize suffering, this is an area that needs to be explored as an option. I have several patients whom I have assessed with dementia who are very determined to have medical assistance in dying as their end-of-life option.

As I said in my presentation, sometimes people have to choose timing in order to balance fear for loss of capacity, and opportunity for advance requests would, I believe, help to minimize that struggle.

[*Translation*]

Mrs. Dominique Vien: Thank you.

We can see that you are very open and very calm when it comes to medical assistance in dying. You said it was important to expand resources and funding.

Do you make that a prerequisite to amending the law?

More precisely, do you want additional funding to be allocated before we make changes?

[*English*]

Mrs. Diane Reva Gwartz: I would suggest that it's a recommendation and not a requirement. MAID practitioners have been doing the work that needs to be done, but it's difficult with the increasing demands, and in order to be able to service Canadians who are making these requests, we will need more resources.

● (2135)

[*Translation*]

Mrs. Dominique Vien: What do you think about the question of minors who demonstrate maturity?

How do you see that?

[*English*]

Mrs. Diane Reva Gwartz: Quite honestly, it's not one that I have had to deal with or have given a lot of thought to. I do believe that age as a cut-off is a number and can be arbitrary. There is concern, for sure, in terms of people having to achieve a certain criteria that may be arbitrary in order to have equitable access to care options.

I believe that it's something that should be explored, but again, would need considerable safeguards to ensure that individual safety is still maintained.

[*Translation*]

Mrs. Dominique Vien: Thank you.

I'm sure my speaking time is running out.

Ms. Baylis, you have apparently experienced...

[*English*]

The Joint Chair (Hon. Yonah Martin): I'm sorry, Madame Vien, your time is up. I apologize for interrupting.

We'll go next to Monsieur Arseneault.

[*Translation*]

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

Ms. Baylis, I want to congratulate you on your nursing career, even though you are now retired. You have seen it all over the course of your career. You have now reached what is called the age of wisdom.

As you know, Canada has offered palliative care for quite some time now; only very recently has it started offering medical assistance in dying. The statistics show that almost 80 per cent of people who request medical assistance in dying have already received palliative care and do not want to end their lives that way. Instead, they want to receive medical assistance in dying. As well, after thinking about it, 20 per cent of people who request medical assistance in dying do not want to receive palliative care.

As a nurse, what are your comments on that subject?

[*English*]

Mrs. Audrey Baylis: I haven't nursed for a number of years, because I had three careers, but I am a registered nurse. Most of the people whom I have been knowledgeable with are 100% behind MAID, because none of us are going to go into a nursing home, one way or another. Right now I still do not qualify to have MAID in Canada because I don't have anything really medically serious at the moment. I don't qualify.

People who want to qualify for MAID don't have that opportunity. That's why I believe so strongly in preplanning while you're still competent, because if I got in an accident tonight, I don't qualify.

Mr. René Arseneault: Thank you, Mrs. Baylis.

[*Translation*]

Ms. Gwartz, I come from an extremely rural area. In face, I think I am one of the rare members of the committee, if not the only one, who comes from an area that is extremely remove from major centres.

When you began your presentation, you alluded to the fact that in Niagara, which is a large populous area, compared to mine, there are not enough resources to offer medical assistance in dying.

Could you tell me more about that, please?

[*English*]

Mrs. Diane Reva Gwartz: Much of the limitations here in Niagara actually have to do with health human resources and providers who are willing to do the work. It's not currently a funding problem. It was when I first started working. As I said, I provided MAID services for three years without any financial compensation. That was because I believe very strongly that MAID should be an option for people in my community, and it wasn't, because we had no providers who could actually get compensation who were willing to do the work.

The current model in Ontario provides funding for physicians to be able to bill through OHIP, but there is no model for nurse practitioners in the community who are competent to be able to provide this care to be able to get compensated. That was a major issue—

● (2140)

Mr. René Arseneault: I'm sorry; is that the case also today?

Mrs. Diane Reva Gwartz: A year ago, I and a colleague led a very strong advocacy program in order to be able to have funding allocated specifically for us here in Niagara, so we do now have funding, but it's just us. It's not throughout the province.

Mr. René Arseneault: In northern Ontario, for example, they do not have that access or that resource.

Mrs. Diane Reva Gwartz: Correct.

Mr. René Arseneault: Wow.

[*Translation*]

As a nurse practitioner, do you have to get training, in Niagara or the Niagara region, in order to offer medical assistance in dying?

[*English*]

Mrs. Diane Reva Gwartz: I am a nurse practitioner, and nurse practitioners are qualified to be able to provide MAID. Any MAID practitioner wants to do training for sure, and there are programs that are actually in process now and being developed, as I understand. When I trained four years ago, it was a self-directed training program. I had a mentor whom I worked with, and I did a lot of self-study, so yes, there was training.

[*Translation*]

Mr. René Arseneault: Thank you.

I imagine my speaking time is nearly up, Madam Co-Chair.

[*English*]

The Joint Chair (Hon. Yonah Martin): Yes, you have five seconds.

[*Translation*]

Mr. René Arseneault: Thank you.

[*English*]

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

Mr. Thériault, go ahead for five minutes.

[*Translation*]

Mr. Luc Thériault: Thank you, Madam Chair.

I would like to address Ms. Baylis.

Your testimony touched me deeply, Ms. Baylis. I don't think there is anything more beautiful than wanting a human being to be able to be surrounded by the people close to them and suddenly feel calm on the threshold of death and surrounded by the love of the people close to them. That really touched me deeply. Thank you for sharing that moment.

You have had quite amazing experience in health care, not just as a nurse, but also as a person. Didn't that help you think about things, for example, to understand these issues of advance directives or advance requests, or preparation? I wonder about something on this subject. You talked about trying to put directives or a process in place at the time a person makes a will. Is it necessary for all that to be notarized, in your opinion?

[*English*]

Mrs. Audrey Baylis: Yes, I would recommend that a document be made, medically and legally and through Parliament as something that all parties agree on, and that it be complied with across Canada.

[*Translation*]

Mr. Luc Thériault: Thank you.

Ms. Gwartz, you talked about problems accessing palliative care and, in that context, medical assistance in dying. In your opinion, it is therefore still very difficult to make palliative care accessible, but also to ensure that it does not preclude medical assistance in dying. In short, you are saying that if a person has access to palliative care, they do not necessarily have the option of requesting medical assistance in dying within that environment.

Did I understand you correctly?

[*English*]

Mrs. Diane Reva Gwartz: Yes. That's true in some institutions for certain, and actually in some communities as well. I can speak mostly to my own community, in which palliative care is quite available. The people here get very high-quality palliative care, but they are not always offered the opportunity to be aware of or make choices related to MAID.

● (2145)

[*Translation*]

Mr. Luc Thériault: So in a way, the slippery slope argument associated with expanding or permitting medical assistance in dying in the terminal phase still generates fear. It seems that palliative care practitioners and their institutions don't always offer the option of having medical assistance in dying as part of their services. That is a situation one would not have believed possible, given that palliative care has been the only solution advocated for 50 years. We understand that this is an exemption.

In your opinion, how could that be resolved where you work?

[*English*]

Mrs. Diane Reva Gwartz: For a start, you could look at how institutions are able to establish these policies.

As I understand it, Prince Edward Island has actually passed legislation that prohibits institutions from preventing MAID in their organizations. I did hear a bit of the previous presenter, Dr. Herx, and I think there's a lot of disconnect. I think that MAID is not part of palliative care. MAID is a different part of health care, medical care, but it is part of end-of-life care. It's an end-of-life option and it needs to be seen that way.

It's unfortunate that there is, as I said, a disconnect or disharmony between some palliative practitioners and the practice of MAID.

[*Translation*]

Mr. Luc Thériault: It's a serious problem, because they could...

[*English*]

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

Mr. MacGregor, you have five minutes.

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

Ms. Baylis, I'd like to echo the words of my colleague Monsieur Thériault and thank you for sharing that very personal story with this committee on your husband's passing, the journey he took in exercising his wishes, and how he wanted to leave this world surrounded by the love of his life and his family.

In the document that you provided to our committee, you say, and I quote, “I strongly believe that my rights as a Canadian citizen are being violated, as I do not have the opportunity to currently preplan my end of life.” You want to see that medical and legal protocol completed so that any and all outside interference, whether they be political, religious or special interest groups, are removed, so that really it is the agency of the individual that shines through.

Ms. Baylis, in a panel we had in the first hour, we had a physician who was talking about what would happen if someone were to sign an advance directive and many years from the signing of that advance directive, their future self lost capacity but also had a change of heart. Have you ever wondered about that?

Let's say you were to sign an advance directive that was perfectly legal in Canada. Have you ever been personally concerned that you might change your mind in the future but lose the capacity to express that change of mind?

Mrs. Audrey Baylis: I believe that would be part of what the medical and legal people would come up with. That would be all built in. You can change your will at any time, so you should be able to change your mind at any time. I think it would be all part of that protocol lined up and passed through Parliament.

Mr. Alistair MacGregor: We also heard testimony that—

Mrs. Audrey Baylis: I listened to the whole night, so I heard all the contestants.

Mr. Alistair MacGregor: You did. Okay. What did you think when you heard the testimony that some physicians have expressed that there is a stigma attached to ageism, a stigma attached to the way we care for our elderly—a fear of growing old, a fear of decay and losing your capacity? Did you have any thoughts or personal views on what you heard earlier?

● (2150)

Mrs. Audrey Baylis: Well, on some of it I agreed, but like everybody, we have to respect everybody's views. This is where the problem comes in. There are millions of people out there, and we all have different views. We have to somehow come up with something that comes up the middle and we can all agree on.

Mr. Alistair MacGregor: We also heard from palliative care physicians, one of whom stressed that they are there to provide medically assisted life, and that they would make sure that patients have the full understanding of all options available to them to carry that life through to its natural end.

I'm wondering what your opinion is of someone who, through their own free will, enters palliative care, but then maybe decides, “This course of care is no longer for me. I wish to now access medical assistance in dying.” Do you think that the physicians who work in the palliative care world should have some kind of transition plan or be asked to respect the patient's wishes? Do you have any views on that?

Mrs. Audrey Baylis: I believe strongly that they should respect the patient's wishes. Unfortunately, that's very difficult with a lot of doctors. Some of them will not talk about MAID, period. I think that's wrong.

Mr. Alistair MacGregor: Thank you once again for providing your testimony to our committee today.

Madam Co-Chair, I will cease my questions there. Thank you.

Mrs. Audrey Baylis: Thank you.

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

I will turn this over to my co-chair, Monsieur Garneau.

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

We'll now proceed to questions from the senators.

We will begin with Senator Mégie.

[*Translation*]

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

My question is for Ms. Gwartz.

Ms. Gwartz, you were with your mother, who received MAID. If I understood correctly, that is what persuaded you to embrace this practice.

Can you tell us about the rigorous process you follow with your patients who request MAID?

[*English*]

Mrs. Diane Reva Gwartz: Just to clarify, I was already working within the field of MAID before my mother had her assisted death, but yes, I did support her through that.

I'm not quite sure what you mean by the “rigorous process”. I think you're asking what steps are involved in assessing someone for MAID.

● (2155)

[*Translation*]

Hon. Marie-Françoise Mégie: Exactly.

[*English*]

Mrs. Diane Reva Gwartz: Okay.

When someone makes a request for MAID, it can be done in an informal way or often through, as we have in Ontario, a central intake. That's how we get the referrals. I contact them directly by phone and set up an appointment to come to their home. At that point, I ask for consent to be able to check their medical records through the online hospital system so that I can get some background information, so by the time I come to their home, I already have some information about what their health experience is.

When I get to their home, I have three agenda items I usually try to follow. The first is that I explain the entire process of being approved for MAID as well as what the actual procedure involves. The second is that I explain what happens in the actual MAID procedure so that they have an understanding of what it looks like. The third is that I offer them the opportunity to begin the assessment process formally. In this process I complete my initial part of the assessment, understanding from them their personal experience of their journey, their symptoms, what's causing their suffering, what treatments they may have had, what they've been offered and what they have experienced as changes in their life as a result of their illness.

That visit is usually between about an hour and an hour and a half, so I get to know them fairly well, and they get to know me as well.

Depending on what the results of that are, we have a discussion about timing. Sometimes it's just information they want to have at that time. Sometimes they're ready to move forward. At that point, if they haven't already completed the written request, they would do that, and we would arrange for a second assessor to come in to do the confirmatory assessment.

[*Translation*]

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

Senator Kutcher, you have the floor for three minutes.

[*English*]

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

I have three questions—and they should be short—for Ms. Gwartz. I'm hoping you can help us learn more about a MAID assessment through these questions and how data is collected.

Let's say that as a MAID provider. If you're seeing a cancer patient and you're not certain at any point in your assessment, would you seek assistance from a colleague, or would you just come to conclusions on your own about what you should do?

Mrs. Diane Reva Gwartz: There are multiple ways of gathering information. As I said, I usually have access to health records through the hospital system. I would often contact the care providers they are already seeing—a family doctor or a specialist. If I continue to be uncertain about things, then I may speak to colleagues who perhaps have more experience with the health issues that person has or possibly the MAID eligibility criteria and how that would play out in that particular situation.

Through the Canadian Association of MAiD Assessors and Providers, we have a very robust forum that is a confidential opportunity for us to share, and I post on that quite frequently about situations to get feedback from others.

Hon. Stanley Kutcher: It's fair to say that your assessment is thorough. It's not just a fly-by-night thing. You take a lot of time and sort things out very carefully.

Mrs. Diane Reva Gwartz: Most often it's hours. Sometimes it's months. I had one patient whose assessment I was spending a fair amount of time on, probably five to 10 hours a week, and supporting him through his journey for almost three months.

Hon. Stanley Kutcher: These things are not done lightly.

Mrs. Diane Reva Gwartz: Absolutely not.

Hon. Stanley Kutcher: Earlier today we were told that MAID data from the ministry of health cannot be trusted because it's filled out by a MAID provider. Do you agree that you cannot be trusted to provide correct information about your MAID patients?

Mrs. Diane Reva Gwartz: Of course I do not agree with that. We are health professionals. We take all our data collection very seriously and responsibly.

Hon. Stanley Kutcher: Thank you very much.

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

[*Translation*]

Senator Dalphond, you have the floor.

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

My question is for Professor Gaind.

If I understood correctly, he is opposed to offering medical assistance in dying to people whose only problem is a mental health problem, with no comorbidity. In his opinion, there is nothing to justify expanding that.

As a specialist in this subject, has he studied the situation in the Netherlands and Belgium, where medical assistance in dying is available for people suffering solely from mental health problems?

Do the studies done there, in particular the commissions' annual reports, indicate that there is a problem? In the Netherlands, fewer than 1 per cent of cases end in euthanasia; in Belgium, in 2020, it mentioned 21 cases out of 2,444.

[*English*]

Dr. K. Sonu Gaind: Thank you for the question, Senator.

I should clarify that my concern is that offering MAID for sole mental illness cannot be done honestly under our current framework. The whole premise of what our MAID framework has been based on and what the Canadian public has been told is that MAID is being offered for a predictable, irremediable condition. That, fundamentally, cannot be met for mental illnesses. When that criterion can't be met, everything else falls apart.

In terms of the Benelux data, the European data you're speaking of, I will point out that year on year, the psychiatric euthanasia there is seeing regular increases quite significantly. I will also point out that—

● (2200)

Hon. Pierre Dalphond: That's not exact. In Belgium it went down in 2019.

Dr. K. Sonu Gaind: Yes, you're right. I'm looking at the Netherlands data, but what I will point out as well is the risk to the marginalized that this data clearly shows. When you have a fifty-fifty gender balance here for MAID when it's for reasonably foreseeable death up until now, and you expand it to psychiatric euthanasia and you find a two-to-one gender imbalance, that imbalance parallels the number of suicide attempts by women with mental illness. Most do not try again. Most do not end their lives by suicide.

The concern, obviously, is converting a transient suicidality into a permanent death. In that sense, I think the expansion ends up feeding into sexism, ageism, ableism and even racism of marginalized populations, because they are shown to have greater unresolved psychosocial suffering. We have to think about how these policies affect all of our Canadian citizens, not just the ones who will get increased autonomy.

[*Translation*]

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

[*English*]

Senator Wallin is next.

Hon. Pamela Wallin: Thank you.

My question goes to Audrey Baylis, if we could start there.

You talk about being denied your right to choose this in advance. We've talked about this, the catch-22 that goes along with dementia or Alzheimer's. You can't ask in advance, but then once you're diagnosed, it's hard to ask after the fact.

How are you dealing with this? Have you talked to other medical professionals? Are you making a list of things that you think would constitute, for you, intolerable suffering and a situation in which you would like to access MAID? How are you preparing for this, even though you don't yet have the right to do this?

Mrs. Audrey Baylis: Well, I'm 84 years of age and I feel that I've had a very good life.

I have very clearly stated in my document for them to take me somewhere where I could qualify—I know that people went to Switzerland—when they can make a decision, if I can't make it. I have no intention of going into a nursing home. I will do whatever is necessary.

I think about it an awful lot. My friends are in the same situation as I am. We're all getting up there in years. What's our option if we don't want to go to a nursing home? There's only one way out.

I can't understand why people can't talk about death these days. It seems to be a taboo subject. We're all going to die. To me, it's very personal. I have the steps in place for me when I can't look after myself.

Hon. Pamela Wallin: Your friends and your family are very aware of this, and if you have to go to another country, you will.

Mrs. Audrey Baylis: Definitely. My passport is always valid, and there's money in the bank to take my whole family over there. They can party and do what they want. They have to wait to bring my ashes back. If they don't want to bring them back, throw them out to the fish.

Hon. Pamela Wallin: Ms. Gwartz, I'll go to you on this topic.

We've heard the frustration, not just in this session but in other sessions, about people who have taken the ultimate step because they're afraid they won't be cognizant and won't be allowed to make the decision. They actually take their lives much earlier than is necessary because they have the same fears as Audrey has just expressed.

Mrs. Diane Reva Gwartz: Are you asking me if I'm familiar with this?

Hon. Pamela Wallin: Yes.

Mrs. Diane Reva Gwartz: I haven't had any patients, luckily, who have done that, but yes, I have certainly heard of situations in which that's happened. I've actually had patients who have told me that was their plan, because we do ask what they will do if they are not found eligible.

I think it's a difficult situation for patients. That's not a choice they want to make, but they often feel they want to have the autonomy to choose how they want to live and how they want to die, or when they want to die.

● (2205)

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

We'll go to Senator Martin.

The Joint Chair (Hon. Yonah Martin): Thank you, Mr. Chair. I will direct my questions to Dr. Sonu Gaind. I'll ask them together, if you wouldn't mind answering them both.

MAID in Canada is supposed to be for irremediable conditions. Could someone seeking to qualify for MAID for sole mental illness regain the will to live? That's my first question.

Second, you wrote an article called “The next national apology”. Could you explain why you've characterized the Bill C-7 MAID regime as something that will require a future national apology?

Thank you.

Dr. K. Sonu Gaind: Thank you for both your questions. I'll answer them in the order you presented them.

On the issue of whether somebody could regain the will to live if they are qualifying for MAID for mental illness, the AMPQ, the Quebec association, wrote a paper supportive of expanding MAID for mental illness. One of the key authors was actually the chair of the current federal panel. Despite supporting MAID for mental illness, even in their position paper they acknowledge that “It is possible that a person who has recourse to MAID—regardless of his condition—could have regained the desire to live at some point in the future.” They then suggest that assessors will have to answer this ethical question each and every time they evaluate a request.

My point is that our law does not say grievous and irremediable conditions are determined by an ethical decision. It should be a scientific decision. On that there is no question that we cannot make those predictions in mental illness. CAMH and every other group that has looked at this, including the AMPQ, has said that.

In terms of the national apology piece, I think you're referring to the piece that I wrote in “The Conversation”. In terms of that, when you link all of this together, if we're not providing MAID for an irremediable condition, one we can predict in a person to be irremediable, then what are we providing it for? What we find we are providing it for is all sorts of other life suffering that is highly conflated with mental illness.

We are exposing marginalized, vulnerable people who actually could get better. We are providing them false, in my opinion, unscientific assessments claiming that they may have irremediability when no one can actually make that determination. Based on that, these marginalized individuals would receive MAID.

To me, that's something I think our country would need to issue an apology for at some point in the future.

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

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

At this point, I'd like to thank all three witnesses for their testimony tonight and for answering our questions. Your contribution plays an important part in a very difficult and important topic that Parliament is looking at.

Thank you very much, as well for your willingness to come and join us, especially late at night.

Committee members, there are just a couple of very quick things that we need to look at, and it shouldn't take more than five minutes, hopefully. I'll put it in front of you right now.

One is we agree that written briefs would have to be in by May 9 and that they should not exceed 1,000 words. To communicate that, it will be put on the AMAD website in a number of places. If you wanted to go beyond that and actually put out a news release, that's something that requires a motion by the committee.

Is there a desire to put that out, or are you satisfied that if we advertise it on the AMAD website, that will be sufficient?

I don't see anybody raising their hands. It's just something to take into consideration.

Hon. Pamela Wallin: Those people who are interested will be following along. Certainly in the emails I'm getting from people asking to participate, they already know that the website exists.

The Joint Chair (Hon. Marc Garneau): I suspect you're right.

The second point is by way of information, because there was some discussion about whether the committee might request an extension. I think it's premature to do it at this point, but if it is done, I will let you know that based on House of Commons precedents, the report would have to summarize the work done by the committee and recommend that the committee be permitted to continue its deliberations past June 23 and be granted an extension of *x* number of sitting days to present its final report.

I would suggest that it's a little premature for us to make that decision at this point. We still have a number of meetings, but it is something you may want to hold in the back of your mind.

● (2210)

[*Translation*]

The third thing I want to mention is that we are going to meet on Thursday evening for two hours. You may already know that. We have received confirmation that the committee may continue its work on Thursday evening, from 6:30 p.m. to 8:30 p.m.

[*English*]

It will be on palliative care, just to let you know. We're going to be busy on this committee, as you all have noticed. There's no question about it.

Palliative care will be on Thursday night for two hours. The next meeting is next Monday, a week from today. Do you want to reserve the three hours for palliative care, or is there a feeling that two hours will do it on that subject and that we can move on the the next subject, which is advance requests or advance directives?

Mr. René Arseneault: Do you mean for next Monday after this Thursday?

The Joint Chair (Hon. Marc Garneau): Yes, Thursday is on palliative care, but do you want a second full session on palliative care, or are you ready to move on to advance directives?

Senator Wallin, your hand is up.

Hon. Pamela Wallin: Yes. It's not specifically on that question, but is there the possibility of getting some kind of a work plan? We all appreciate how busy this committee is going to be, but we all have other committees as well, and we kind of run on the MPs' schedule, because you have votes and whatnot. We also have our own schedule of committees and work and commitments in our chamber.

Is there some intention that you will actually map that out, so that if a Thursday comes up, we need to be able to plan for that?

The Joint Chair (Hon. Marc Garneau): We live in an imperfect world, Senator.

At the moment, the plan is two sessions per subject. If we find as we go through them that we need a bit more, we'll have to cross that bridge when we get to it. We haven't a whole bunch of sessions ahead of us, but at the moment, the plan is for two per subject. What I was bringing up tonight was a way of perhaps fine-tuning it a bit if people thought that maybe, in the case of palliative care, one session might be enough.

The other thing, of course, is that we don't know when those Thursday nights will be liberated. We'll do four sessions—

Hon. Pamela Wallin: Yes. That was more my question.

The Joint Chair (Hon. Marc Garneau): Yes, we're going to have to play that one by ear. The BOIE is not going to give us advance notice a long time ahead of time. We have to be a bit nimble on this.

A work plan would be very nice, but I can't do anything better at this moment other than ask if you want to have two sessions per subject matter, and we can fine-tune as we go along. As I was suggesting tonight, it's something that you'd maybe want to consider, or do you want to keep next Monday night also for palliative?

Go ahead.

Hon. Pamela Wallin: I'm fine to go to advance practice. I'm great with the other issue, which is the maximum notice that we can get. If you only just discover that we are meeting next Thursday or this Thursday night, it would be really helpful if we could be informed of that as a membership as quickly as possible. That was—

The Joint Chair (Hon. Marc Garneau): Believe me, we are trying to do that. We're doing it. We're doing this in real time all the time.

Go ahead, Monsieur Arseneault.

[*Translation*]

Mr. René Arseneault: Personally, I propose that we complete the discussion of palliative care on Thursday, as scheduled, and move on to another subject next week.

● (2215)

[*English*]

The Joint Chair (Hon. Marc Garneau): Okay.

Did you have your hand up, Mr. Maloney?

Mr. James Maloney: I was going to say exactly the same thing, but Mr. Arseneault said it. Tonight, we essentially dealt with palliative care.

The Joint Chair (Hon. Marc Garneau): Go ahead, Senator Kutcher.

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

First of all, I'd like to thank you for raising the potential for an interim report, or not a complete report. It's something we can think about as we go forward. I think this is such an important topic that to be rushing it would not be fair to the people who are waiting for this report.

The second thing is on palliative care. Would the witnesses we are going to hear be able to resolve a conundrum that came out of the discussion we heard today? There were some people saying that funding for palliative care has gone down. Other people were saying funding for palliative care hasn't gone down and that in fact more people are getting palliative care. It's hard for me to square that circle. I don't know the answer to that. We really need to know the answer to that. That's a very fundamental point.

Do the witnesses we're going to hear next time have that information, or is it something that the Library of Parliament could provide for us if we asked for it? I don't know enough about how this should work.

The Joint Chair (Hon. Marc Garneau): You're right that we heard different opinions, but I don't know if the witnesses.... I can't predict whether they will shine the proper light on it or not. If there continue to be two camps, perhaps we could ask for some help from the analysts or—

Hon. Stanley Kutcher: Right. This sounds to me like it's fairly factual. One could get data province by province and by territory and look at the budget lines and what happened and see how many people have received palliative care over that time, etc. That should be possible.

The Joint Chair (Hon. Marc Garneau): Hopefully, we will get six witnesses this Thursday. Perhaps they will all lean in the same direction and give you a better sense of who's right. That's part of the job.

People have different opinions, unfortunately. I know it's factual, as you say, but perhaps we'll uncover that.

Hon. Stanley Kutcher: We're all entitled to our opinions, but facts are a different issue.

The Joint Chair (Hon. Marc Garneau): Yes, facts are facts.

[*Translation*]

Does anyone else want to say something?

[*English*]

I have some hands on the screen. I'll start in the top left corner.

Go ahead, Mr. Barrett.

Mr. Michael Barrett: Thank you, Mr. Co-Chair.

With respect to Senator Wallin's discussion about a work plan, I wonder if it wouldn't be prudent to produce that as soon as possible. The reason is that when we discussed the amount of time the analysts needed to produce reports of certain lengths, we were expecting to have four three-hour meetings. Now there are discussions to add as many as 12 hours to the week of May 22. I wonder what impact that would have on the analysts' ability to produce a report of 10 pages or longer.

Further, with respect to the conversation about how many meetings we're having on each subject, I would say that the questions of palliative care have not been resolved. To look back, Senator Kutcher had a further question on the subject. I think there's more to hear there. If we're potentially adding an additional 12 hours of meetings, I wouldn't want to prematurely move on to another issue or another subissue, as it were.

I believe we need a work plan, something we can discuss or that the subcommittee could convene on or discuss, or at least sidebar about, before we come back to a full meeting.

Thank you.

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

On the question of whether next Monday we should stay on the same subject, I think you're leaning in the direction of a second session on palliative care.

Mr. Michael Barrett: Yes, sir.

The Joint Chair (Hon. Marc Garneau): With respect to the work plan, there are a couple of issues we're working on at the moment. I think we're going to have to get together as a subcommittee.

The first—and this has an influence on the analysts' work—is how big a document we want to produce at the end. There's a big difference between 10,000 pages and 20,000 pages. That's something we need to decide, because that has an influence on how much time they need at the back end of this to prepare that report.

Then another factor is the translation. The translation services are probably the commodity most in demand at the moment, and that also can back us up as well. That's why we haven't quite nailed down a firm, predictable work plan at the moment. It's because we're having to deal with that. I will be asking the subcommittee to talk about this, because we need to figure that out.

Then we may be in a better position to put together that work plan that you're looking at, but please bear with us as we try to answer a couple of questions before that so that we're in a better position to put out that work plan.

Mr. Michael Barrett: That's very helpful. Thank you, Mr. Co-Chair.

The Joint Chair (Hon. Marc Garneau): Go ahead, Ms. Fry.

● (2220)

Hon. Hedy Fry: Thank you, Chair.

I wanted to suggest that the issue of palliative care is not actually resolved. However, I think Senator Kutcher made a very good point when he raised the question of whether palliative care services are going down in different provinces. This is not a federal thing. If palliative care services were going down, it would be a provincial thing.

That's factual data we can get. If palliative care services are going down, we can get that data. If those services are going down and being replaced by MAID services, that's something we can also get the Library of Parliament to research for us.

We have not very many meetings coming up, and we still have not touched on the very difficult and thorny issues. Mental health, mental illness is a single issue. We have not discussed minors. We need to get our teeth into that, because those are really complex issues. I think the palliative care issues are clear and factual, but these others are really cognitive issues, complex issues that we need to get to the bottom of.

I think we should move on to something else at the next meeting. We can get information on palliative care and come back to it when we get the information from the Library of Parliament.

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

We agreed that we would go with palliative care as our first area of study. Now perhaps we can put in a request to the Library of Parliament to dig up the information that Senator Kutcher is asking for, but I think we should go with palliative care for this Thursday. I don't think we should bring everything to a grinding halt on that at this particular point.

Your point about getting some assistance from the Library of Parliament, perhaps, to answer the questions is a good one.

I go to my fellow co-chair, Senator Martin.

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

In regard to Senator Wallin's question about Thursday, I didn't get a chance to communicate with all the senators because it was happening in real time, but I'm going to make it a top priority to ensure that information is shared more quickly. I just wanted to let Senator Wallin and my colleagues know.

Regarding palliative care, it's a very important and complex issue. Beyond getting some of the numbers, I think we need to hear more about it. A review of palliative care should have been done, and we didn't have a chance to assess the lay of the land, especially how it intersects with MAID.

I would strongly recommend that we keep two sessions per topic. They are all complex in my opinion.

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

[*Translation*]

Senator Mégie, you had raised your hand, I think. Forgive me, I didn't see it.

Right. You've had your answer.

Thank you, colleagues.

Does anyone else want to comment?

Mr. Anandasangaree, you have the floor.

[*English*]

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

With respect to a subcommittee meeting, is it possible to schedule one this week outside of the schedule for MAID? I think we need about an hour so we can hammer out some of the outstanding issues that we discussed at the subcommittee last Wednesday, and that would resolve a lot of the discussions that we're having today with respect to palliative care. At this point, if we do a two-hour session on Thursday on palliative care—I believe a number of witnesses spoke on that issue today—we can probably do a two-hour session next Monday, May 2, and then have the last hour for some other item we can move on to.

● (2225)

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

When we can have a subcommittee meeting, we need to have one, because this is certainly something we need to deal with. I can't answer your question, but we'll get back to you as quickly as we can.

Go ahead, Mr. Thériault.

[*Translation*]

Mr. Luc Thériault: Mr. Chair, first, we know that we will be meeting this Thursday. That's a good thing since the Board of Internal Economy, the BOIE, won't be sitting on Thursday. That will allow us to meet.

However, we don't know whether the BOIE will be sitting next Thursday or not. Before meeting in subcommittee in a situation we don't know, I would prefer that we take some time to hold a meeting in subcommittee after our Thursday meeting, but not before Thursday.

At present, we are kind of going in circles. We don't have the information we need to establish a work plan. What we established was that there would be no extension of our work, at least for now. According to the work plan, we had to meet the June 23 deadline, which was a bit unrealistic, in my opinion, but fine, we have already debated that question, last time.

We now know that four three-hour meetings would be added during the break week, but let's wait a bit to see how many BOIE meetings we will have for establishing a work plan.

Meeting this Thursday to discuss palliative care, that works. After that meeting, if we don't have any more information, we will see whether we are going to continue on that subject or move directly on to advance medical requests. That is my position.

As for us, I think we have a pretty full week.

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

The only problem is that if we decide on Friday not to hold a meeting on palliative care next Monday and to choose another subject, it will be too late to call witnesses.

I'm hearing people say they would like to have a second meeting. Others think one meeting is sufficient. That said, I think it would be preferable to have a second meeting.

Senator Dalphond, you have the floor.

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

I would just like to make one little comment. I sense that we want to work quickly. I am finding it a bit hard to proceed this way without having the documents from the people testifying before us.

Today, several witnesses referred to what they had said in their briefs, which we have not seen. I admit that I would have liked to ask them questions based on their briefs and not hear a summary of their briefs. Because then, if I have questions to ask them, the witnesses won't be there.

Regardless of the topics you want to study and the order in which you want to do it, I would suggest that the written documents arrive before the witnesses appear. If translations and documents are ready now for next week, I will be prepared to play with the topics to hear the witnesses' views after reading their briefs. In fact, it is very rare for me to take a position on something without having read the documents from the person testifying.

The Joint Chair (Hon. Marc Garneau): I understand the logic behind what you're saying.

Again, the problem is that we can't require that witnesses provide us with their documents in both official languages when they are going to appear. They can send us documents. If they send them and the documents are in only one language, we have to have them translated before giving them to you. We can't give you documents translated into both languages in time for the meeting unless they are already bilingual. It's an inconvenience, but if we proceed that way, it will prolong our timetable considerably, unfortunately.

Remember, it was only a few days ago that we started to contact all the witnesses to invite them to appear, so as not to lose any time. They can't provide us with their briefs in both official languages before they appear. In some cases, they are not obliged to send us their briefs. They can send them after they appear, if they wish.

[*English*]

It's late in the evening, but I think for the moment there are three things that come out of this.

We should ask the library to do a little bit of research on the questions with respect to palliative care that you raised, Senator Kutcher.

We will try to have a subcommittee—I can't tell you exactly when—to discuss something towards having a work plan, but that will be based on our making decisions about the size of the document and those kinds of things.

The third thing, for the moment, is that given that there are different points of view, I would suggest that we plan to discuss palliative care both this Thursday and next Monday night. Is that something you can agree with for the moment?

Just a moment, Hedy. Our analyst Marlisa had her hand up first.

Go ahead.

● (2230)

Ms. Marlisa Tiedemann (Committee Researcher): Thank you.

I'm really sorry. I'm not trying to complicate issues.

Absolutely, we will make a request to the library to see if they can find data relating to provincial spending pre- and post-MAID with respect to palliative care. Unless somebody has already done that research, it will likely [*Technical difficulty—Editor*] so we'll do our best.

If the committee wishes to go ahead with an additional meeting on palliative care, most of the witnesses who had been identified in the work plan have been exhausted, with the exception of those on the Liberal witness list. I offer that if that helps people determine whether or not we need or would like to have another meeting on palliative care. We would need more witnesses from some of the parties to be able to do another full meeting.

Thank you.

The Joint Chair (Hon. Marc Garneau): You're saying we don't necessarily have witnesses. If we get six witnesses this Thursday, we will not have more witnesses to fill up the next session.

Ms. Marlisa Tiedemann: We have identified three panels and nine witnesses, but after that, there wouldn't be a balance of perspectives on panels beyond those three panels.

The Joint Chair (Hon. Marc Garneau): Okay.

Go ahead, Mr. Cooper.

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

On that point, from our side there are a number of names we could provide, so that would not be an issue.

The Joint Chair (Hon. Marc Garneau): That would not be an issue. Those would have to be provided very quickly.

Now it's Senator Wallin, but we need you to put your headset back on. Hedy, you can do yours too while you're waiting.

Go ahead, Senator Wallin.

Hon. Pamela Wallin: Because we've run through the list of witnesses, I think we should maybe move on. We can always come back to palliative care if the data suggests there is something there that we need to really drill down on. I agree with Hedy that we really need to move on to other issues.

Our time has been so crunched because this committee was not convened, and now we're trying to cram and meet at all hours of the night and day. There were comments made about how we had agreed to do this and we had agreed to do that, which I was not informed about, and as I say, our schedules are very different. We travel at different times. Some of us go to places that are difficult to get to.

I'd like to make sure that at the very least we hit all of the major topics in the time we have allotted in case extra days don't come up or in case some of us can't participate, and then, maybe sooner than later, we can have that conversation about asking for more time so that we might be presenting an interim report, because this schedule is nothing short of insane for topics that are so fundamental. That's what really concerns me.

Thank you.

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

Go ahead, Ms. Fry.

Hon. Hedy Fry: Thank you.

This is a mutual admiration society. I agree with Senator Wallin, because whatever information we get about palliative care from our data gathering we're going to have to discuss anyway, whereas as we move on to different aspects of this study, we might find that we want more information on certain things.

If we can start off, do all the pieces, look for the information and have it coming back to us so we can discuss it, that would make far more sense to me than having people tell us about palliative care at the next meeting and finding out that they still haven't answered our issues and our questions. It just doesn't make logical sense to me for us to do it this way. I think we should get the information we need first and then go back to palliative care.

● (2235)

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

Do I see anybody else?

[*Translation*]

Senator Mégie, you have the floor.

Hon. Marie-Françoise Mégie: Mr. Chair, is it possible to have a show of hands to determine whether we are going to devote one or two meetings to palliative care?

The Joint Chair (Hon. Marc Garneau): It's possible.

[*English*]

Let me just frame one thing here. We're trying to move forward and use our time as productively as possible. As a work plan, we have to be ready to adjust as we go along, but we need to move forward on this and use our time as wisely as possible.

Senator Mégie has suggested that we should take a vote on whether next Monday we move on to another topic or whether we devote the second meeting to palliative care. I'm going to ask for a show of hands for those who are here. Those who would like to do palliative care this Thursday but move on to something next week, please show your hands.

That looks like a majority. That was very clearly to do just palliative care this Thursday and move on to what would be advance requests or directives starting next Monday.

As a committee, you can choose to come back to something later on, but for our purposes now, I think a majority want to do palliative care this Thursday and advance directives next Monday.

Is there anything else?

Thank you.

This meeting is adjourned.

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