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# Special Joint Committee on Medical Assistance in Dying

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





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• (0845)

[*Translation*]

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

Today is the 21st meeting of the Special Joint Committee on Medical Assistance in Dying.

I would 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 Joint Chair of this committee representing the House of Commons, together with the Honourable Yonah Martin, the Joint Chair representing the Senate.

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.

[*English*]

I would like to remind members and witnesses to keep their microphones muted unless they're recognized by name by a joint chair. As a reminder, all comments should be addressed through the joint chairs.

When speaking, please speak slowly and clearly. Interpretation in this video conference will work like in an in-person committee meeting. You have the choice at the bottom of your screen of floor, English or French.

With that, I'd like to welcome our witnesses for panel one, who are here to discuss the state of palliative care in Canada. As individuals, we have Julie Campbell, a nurse practitioner joining us by video conference, and Dr. Nathalie Zan, whom we hope will be on very soon. We also have, from the Christian Legal Fellowship, Derek Ross, executive director.

Thank you all for joining us this morning. We will begin with opening remarks by Ms. Campbell, followed by Mr. Ross and Dr. Zan. Hopefully Dr. Zan will have joined us by then.

Ms. Campbell, you will have five minutes to speak. The floor is yours. Please go ahead.

**Ms. Julie Campbell (Nurse Practitioner, As an Individual):** I want to thank you for the opportunity to speak with you today.

I'm here as an independent nurse practitioner and MAID provider, and I speak with the experience of supporting access throughout Ontario.

I want to start by sharing my appreciation for your support of the CAMAP national MAID curriculum project. I also acknowledge the good work done to establish the waiver of final consent to allow patients to fully optimize their pain and symptom management without fear that a loss of capacity would limit their choices. This work can continue by establishing advance directives specifically to address patients with conditions that by their nature will progress to impair capacity.

In previous testimony, you've heard references to the mounting research on the importance of identifying patients early for palliative care. I echo those comments and fully support education to integrate a palliative approach to care in all care settings.

Practitioners involved with MAID share concerns about late referrals. Of the 3,228 patients I was involved with who expressed an interest in MAID, only slightly more than half decided that MAID was the right choice for them. Many others did not proceed but had a choice. I believe that information can be a step toward reducing fear and uncertainty. Information doesn't promote MAID. It encourages progressive discussions with care providers and loved ones and encourages informed, thoughtful patient choice.

I echo the previous testimony on the high percentage of patients receiving MAID who also receive palliative care and the suggestion that we should continue to aim higher. This isn't just measured in percentages, but also in the level of interdisciplinary supports available and the reduction of barriers. Measurement of the quality and access of palliative care should be done within palliative care. Patients who choose MAID are only a small group, so it is important not to miss the experience of others.

MAID is not a failure of care. It is a choice about how one dies. I would add that the patients most likely to receive palliative care are those diagnosed with malignancies. We need greater identification of patients with serious life-limiting chronic conditions and even more focus on our frail elderly or patients with dementia who are least likely to be identified and to receive palliative care supports.

I'd like to complete my statement today with some suggestions for improving palliative care and MAID in Canada.

We need to leverage the successes demonstrated from interdisciplinary patient-centred teams of professionals and focus on those least likely to be identified for palliative supports. Federal statistics identify that the percentage increase in MAID provisions outpaces the increase in number of providers and, in particular, the number of providers with the experience to take on the increasing complexity of this work. This data does not acknowledge the health human resources needed to provide education and assessment for those who do not proceed with MAID.

Patients seeking MAID also need integrated teams. Some provinces offer some of this integration, but others significantly less. MAID has been described as a procedure. I think that's an oversimplification of the relationships fostered and the thoughtful, careful assessments that give us such insights into patients and suffering through their eyes.

As we increase the complexity of patients who may be eligible, we need to access expertise in a variety of conditions, including services with significant waiting lists, like specialty pain and psychiatric supports. We need coordination and administrative supports; mental health, social work, nursing and social supports; and an ability for clinicians to travel and optimize virtual care to promote equity. An additional advantage of building these teams would be to provide remuneration for nurse practitioners, who remain without the independent funding support provided to physician colleagues. They play an important role in ensuring access.

We need to remove organizational barriers to integrated care that force transfers of patients in their moments of greatest vulnerability. We also need targeted federal health care transfer payments to bridge the gap between federal legislation and provincial implementation. We must ensure that integrated, interdisciplinary MAID access isn't just legal, but an available choice.

Thank you.

● (0850)

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

We'll now go to Mr. Ross.

Mr. Ross, you have five minutes.

**Mr. Derek Ross (Executive Director, Christian Legal Fellowship):** Thank you, Mr. Chair.

Good morning, and thank you to the committee for this opportunity. My name is Derek Ross. I'm the executive director and general counsel for Christian Legal Fellowship. We are a national organization of lawyers and an NGO that has special consultative status with the United Nations. CLF also intervened at all levels of court in the Carter case.

I think it's important to look at that decision in our deliberations and discussions today. The Carter case, as you know, called for the legalization of MAID, but only for competent adults who are irremediably suffering, fully informed, non-ambivalent, clearly consenting and free from coercion or duress, and only in the context of a carefully designed system imposing stringent limits that are scrupulously monitored and enforced.

It's important to review our compliance with that criteria and how we can ensure the conditions necessary for a patient's choices to truly be, in the words of Carter, "non-ambivalent", "voluntary" and "fully informed". One such condition is that a patient should have meaningful access to quality services that can alleviate their suffering, such as palliative care. If a person wants to live but is accepting death because they lack basic supports, then they haven't made a free choice at all.

The Criminal Code requires that all patients be "informed of the means that are available to relieve their suffering" before MAID. However, palliative care and/or disability supports were not accessible in hundreds of cases of MAID thus far, according to Health Canada. Even where they were accessible, their adequacy and quality were unclear from those reports. A number of other concerns have emerged, which are set out in our brief and which have been echoed by United Nations human rights experts. Canadians must know that these concerns are being investigated and addressed. It is not enough to simply report on safeguards; the government must, in the words of Carter, "scrupulously" enforce them.

Provision of MAID in circumstances where reasonable supports are lacking may also raise charter concerns. As we explain in our brief, if the government were to offer death as the only accessible option for patients while failing to deliver health care in a reasonable manner, it could be interfering with the right to life and security of the person, protected by section 7 of the charter.

Previous witnesses have raised concerns about inadequate resources and funding for palliative care and a lack of public awareness about what it offers. It is crucial to address these concerns, especially, we would add, in the pediatric context. The CCA expert working group observed that "little is known about how mature minors make meaning of end of life care". We need to know more about how specialized pediatric palliative care can be prioritized to better support youth.

Neither Carter nor Truchon required MAID for minors. They certainly did not require involuntary euthanasia for infants, no matter how severe their disability nor how short their predicted lifespan. We would urge this committee to reject any proposal in that regard, such as what was proposed before this committee. It would eliminate the requirement of consent, which infants cannot provide, and would infringe the charter's protection of the right to life and the right to equal protection of the law without discrimination based on disability. This is not to deny that Canadians of all ages who are suffering deserve better solutions. They do. It is because they do that we must prioritize palliative care.

We would recommend that all patients not just be informed but be offered consultations with professionals who provide care to relieve their suffering, including palliative care. Those are patients in track two and track one. We would also endorse the observation that the Standing Senate Committee on Legal and Constitutional Affairs made last year: "The Government of Canada should create an oversight body or mechanism to ensure compliance with MAID regulations and to oversee that appropriate accountability and medical care have been provided to all patients".

I look forward to your questions. Thank you again for the opportunity to present today.

● (0855)

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

Before I turn it over to my co-chair, I just want to confirm that Dr. Zan has not yet joined us.

I'll now turn it over to my co-chair, Senator Martin.

**The Joint Chair (Hon. Yonah Martin (Senator, British Columbia, C)):** Thank you very much.

Thank you to our witnesses this morning. Your testimony will be very valuable for the study we are doing at this time.

We will begin with questions from members of Parliament.

Mr. Cooper, you have five minutes.

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

I will direct my questions to Mr. Ross.

Can you speak to the legal distinction between palliative care and MAID? We hear about the continuum of end-of-life care involving both palliative care and MAID. Can you clarify the legal distinctions?

**Mr. Derek Ross:** To address that, I would direct the committee to legal principles in a couple of areas of our case law and legislation, starting with Carter. In the trial decision in Carter, the trial judge defined palliative care and assisted dying separately.

The court defined palliative care as treatments aimed at alleviating suffering. It aims to neither hasten nor postpone death but affirms life and regards dying as a normal process. That was at paragraph 41 of that decision. Assisted dying, on the other hand, involves the intentional termination of the life of a person at their request.

Those practices were recognized as distinct in Carter. Palliative care exists to improve the quality of life throughout life and throughout the natural dying process. MAID involves an intentional act to terminate the life of a patient at their request. In fact, in Carter, the trial court, after reviewing the evidence, observed that adequate palliative care can reduce requests for euthanasia or lead to their retraction.

That also led to another—

**Mr. Michael Cooper:** That dovetails into my next question. Can you speak to what the courts have said about palliative care as a safeguard in the context of MAID?

**Mr. Derek Ross:** Yes. That was also discussed in Carter. One of the aspects is ensuring that a patient who receives MAID or at least seeks MAID has the benefit of informed consent and has information about all available options. In Carter, the trial judge said that the range of treatment options described would have to encompass all reasonable palliative care interventions in order for that informed consent standard to be met.

The trial judge in that case required that the plaintiff be referred to a physician with palliative care expertise for a palliative care consultation before proceeding with MAID. That was something that the trial judge wanted the treating physician to certify.

That's also reflected in the preamble to the Framework on Palliative Care in Canada Act, which states:

a request for physician-assisted death cannot be truly voluntary if the option of proper palliative care is not available to alleviate a person's suffering

That refers to the final report of the external panel on options for a legislative response to Carter. Certainly the case law suggests and, in fact, affirms that information and access to palliative care are important for there to be informed consent for patients seeking MAID.

● (0900)

**Mr. Michael Cooper:** Thank you for that.

You spoke about the Carter decision at some length. We hear a lot about autonomy, and the court certainly recognized individual autonomy in making a choice with respect to MAID. However, the court also talked about balancing that against the real risks involving vulnerable Canadians.

Can you elaborate on what the court said in that regard?

**Mr. Derek Ross:** I think it's important to remember how the court in Carter framed the issue. The court said that MAID would be an exception, a stringently limited exception, that would be "scrupulously monitored", and the stringent limits would be scrupulously enforced precisely because there are inherent risks in any regime that permits assisted death. That's not—

**The Joint Chair (Hon. Yonah Martin):** Thank you very much, Mr. Ross.

Next we'll have five minutes for questions from Monsieur Arseneault.

[Translation]

**Mr. René Arseneault (Madawaska—Restigouche, Lib.):** Ms. Fry will be speaking now, Madam Chair.

**The Joint Chair (Hon. Yonah Martin):** I'm sorry; you're right.

[English]

Dr. Fry, I reversed the order by mistake. You have the floor for five minutes.

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

I want to thank the witnesses for coming once again and exploring with us some of the questions we need to ask about this very important topic.

I think what I heard from Mr. Ross is that palliative care is an actual continuum or spectrum of care as a person seeks MAID, and palliative care is an integral and important part of that. What I'd like to find out is this. As you well know, inherent in the Carter decision is the idea that this is about the patient's fully informed choice, as you mentioned. However, it is a normal part of practising medicine that you must fully inform your patients of all their options in treatment and care before they start making choices.

As Carter said, if this is about the patient's decision eventually, for whatever reasons, once they're fully informed, what do you think would happen if the patient decided that given all that information, they did not want to go into palliative care? That's the first question I want to ask you.

The second question I want to ask is about whether or not palliative care, which is in provincial jurisdiction, is readily available for a particular patient. We've heard the stories that sometimes they're not ready or they're not available, or the patient doesn't have an ability to live life because they don't have support systems. If all that is there and is available to them, do you believe they must have palliative care, or do you believe there is still an option based on informed consent?

• (0905)

**Mr. Derek Ross:** Thank you so much for those thoughtful questions. I'll do my best to address them. They are very important.

At the outset, though, you indicated that you thought you heard me say that palliative care and MAID are part of a continuum. That is not what I am suggesting. In fact, I think it's important to recognize that these are distinct practices. These are distinct fields that were recognized by the framework on palliative care in Canada.

**Hon. Hedy Fry:** Yes, I understand that, and I'm sorry if I... What I'm saying is there is a continuum of care in any care. It's the whole bandwidth of care that's available to a patient. Palliative care is part of that; MAID is another part of that. I'm not suggesting that the two are conflated.

What I'm asking is that given fully informed consent, do you think the patient, under Carter, has the right to refuse palliative care? Do you believe, in fact, if palliative care and everything is available, that the patient eventually is the one who will make that decision?

**Mr. Derek Ross:** Yes, I think Carter is clear that a patient cannot be forced to undergo treatment that is unacceptable to them, so that is certainly part of the consideration.

As you said, the emphasis here is on a patient's choice. What we're trying to emphasize today is the choice for patients who are seeking palliative care, or at least who want to explore it but currently don't have the ability to do so because of a lack of access or information. That is so important for us to be emphasizing in this question around choice.

**Hon. Hedy Fry:** I'm sorry, Mr. Ross, but I don't have a lot of time and I want to ask you one more question.

Given that there is a spottiness in the provincial jurisdictions and in availability in different provinces, what do you think the federal government should do to ensure that patients have their full choice?

**Mr. Derek Ross:** That is such an important question.

I think first and foremost there needs to be a prioritization of this issue at the federal government level. They've done some great work with the framework, but that needs to be implemented. That requires very close and concerted coordination and implementation with the provinces.

One thing I think the federal government can do is prioritize the re-establishment of the office of palliative care, which would be an office in the federal government to help coordinate these efforts and ensure that this is a policy priority being advanced and worked on in conjunction with the provinces. The federal government can also earmark funding for palliative care projects, supporting organizations that work in this area that try to provide logistical support to patients and families who are seeking access to palliative care.

**Hon. Hedy Fry:** Chair, do I have any more time? How am I doing here?

**The Joint Chair (Hon. Yonah Martin):** No. We're at five minutes now. Thank you, Dr. Fry.

**Hon. Hedy Fry:** Thank you very much.

**The Joint Chair (Hon. Yonah Martin):** Colleagues, I have to pause here to recognize that Dr. Zan, our third witness, has now joined us.

Dr. Zan, would you turn on your camera? We hope the sound will come through. We know that you don't have the headset we sent you.

We'll give you the floor at this time—if that's okay, colleagues—to hear from you.

Go ahead, Dr. Zan.

**Dr. Nathalie Zan (Doctor, As an Individual):** Hello. I hear you very well.

Madam Chair and honourable members of the committee, I have a written statement, which I prefer to read. It will be more comfortable. I will be addressing you in French.

[*Translation*]

My sincere thanks for inviting me to appear before the Special Joint Committee on Medical Assistance in Dying. This is a subject that is of particular interest to me. The objective of this testimony is to tell you about the challenges I see when it comes to access to the continuum of palliative care, including medical assistance in dying.

I have been a family physician in Quebec since 1993. My field of practice was very general in the beginning, but since 2009 I have worked mainly in geriatrics. I have had the opportunity to practise family medicine and geriatric medicine in virtually every setting, in all types of general medicine practices. I have also been a medical manager for several years.

Caring for patients who have irreversible and incurable diseases is an important part of my everyday work, and I have administered medical assistance in dying several times over the last few years, so I want to tell you about my experience.

The demographic changes we are experiencing, that become more apparent every day, mean that the need for palliative care and requests for medical assistance in dying are rising exponentially. Despite the efforts made to develop these kinds of care, there are still limits on access to them.

I observe that each person's experience can be very different, for a variety of reasons. Some examples come to mind.

First, there a person who is in hospital and needs palliative care and is waiting for a single room, to which they are entitled. In the health institution where they are, there are not enough single rooms, and the person dies in a two-person room or in a ward. Too many people are still dying in the less than optimal environment of our dilapidated institutions that offer poor accommodation for both the people being cared for and their families.

Second, people at the end of life are often waiting for a bed in the palliative care unit, but the number of beds is limited. Some people receive a bed only at the very end of the course of their disease. Often, they are unconscious when they are transferred there; sometimes, they die without a bed being found for them.

Third, a person suffering from a non-cancerous chronic disease who requires specific palliative care may have more trouble accessing that care, given the limited number of beds in palliative care units.

Fourth, a patient living alone at home who is waiting for palliative home care services to be arranged may have to attend at the emergency room. Given the rising number of seniors who are living alone, this problem may arise more often.

Fifth, one of the admission criteria for a bed in a palliative care unit is that the person have less than three months to live. Individuals with a serious loss of autonomy with more than three months to live are often directed to the CHSLDs, regardless of their age and diagnosis. A person then admitted to a CHSLD is not in the right place to get the best palliative care. As well, they are unfortunately occupying a bed that is ordinarily reserved for seniors with very different needs, including specific palliative care. As well, some of these people die in less than three months without receiving optimal palliative care, unfortunately.

Sixth, some people who request medical assistance in dying have their access limited to certain palliative care beds in institutions that do not offer this type of care. Some of these people die without having access to optimal palliative care.

Seventh, some patients admitted to a palliative care institution have to change institutions in order to receive medical assistance in dying, since it is not offered in the institution where they are at the time.

Eighth, there is the issue relating to respect for the wishes of people who become incapable.

I believe we have to examine the level of care and the quality of the care offered and the services to be developed for the continuum of palliative care, which includes medical assistance in dying. The present shortage that affects every interdisciplinary professional team also makes this examination necessary.

I would stress that we are very fortunate to live in a society that allows and encourages the expansion of the available palliative care. In my area of practice, the east end of Montreal Island, the demand for medical assistance in dying is rising steadily. I am sure that this is the case everywhere in Canada.

Every day, patients ask me about medical assistance in dying and palliative care. Being able to choose care that is appropriate for their needs gives them reassurance. However, they are still worried about their wishes being respected and about access to their choice. Certainly, we have to continue working on educating our professionals and raising their awareness.

You and I do not know in advance what care we are going to choose in an end-of-life situation, which is where we will all inevitably find ourselves. My wish for you all is that we be able to be accommodated and that our ultimate and deeply personal choice be respected, and that we have access to all the care we need when the time comes.

Personally—

● (0910)

[*English*]

**The Joint Chair (Hon. Yonah Martin):** I'm sorry, Dr. Zan, but we have gone beyond five minutes. Thank you very much for your testimony.

**Dr. Nathalie Zan:** Thank you.

**The Joint Chair (Hon. Yonah Martin):** We will return to our questions.

Next we have Mr. Thériault for five minutes.

[*Translation*]

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

My first questions will be for Dr. Zan.

Some people tell us there is no choice at present. You have described access to palliative care. Some people say the reason people request medical assistance in dying is that they do not have access to palliative care. Is that also your opinion?

• (0915)

**Dr. Nathalie Zan:** No. These are two totally different things. Obviously, there is insufficient access to palliative care, but that is not the reason why people request medical assistance in dying. I think both must be equally accessible. Medical assistance in dying is not an alternative to palliative care.

**Mr. Luc Thériault:** You said that all patients in the terminal phase, that is, who have less than three months to live, have trouble getting access to care. You also added something that threw me: someone who went to the hospital and said they wanted medical assistance in dying would be denied access to the palliative care unit. They would not have access because they had chosen medical assistance in dying.

**Dr. Nathalie Zan:** It think it depends on where the person is.

**Mr. Luc Thériault:** We are not talking just about hospitals. You say that someone who requests medical assistance in dying has to be transferred elsewhere when the institution where they are, for example a home, does not practise it, or when no one agrees to provide it.

**Dr. Nathalie Zan:** It can happen. In some institutions, there is no problem, because there is a continuum of care. However, there are cases where a person might be admitted to a palliative care unit in an institution that does not offer access to medical assistance in dying. That person would then have to go somewhere else to receive the care they want. The reverse is also true. It can happen. It is not the case everywhere, but it happens.

**Mr. Luc Thériault:** Some people say that palliative care covers much more than the end-of-life care phase. The Quebec statute is called the Act respecting end-of-life care. Obviously, as you said, palliative care is part of end-of-life care. What Quebec has done, with its law, is decide that a request for medical assistance in dying could be made as part of end-of-life care and must be accepted. The title of the law is not about medical assistance in dying; it is the Act respecting end-of-life care. So a continuum of care is offered that includes medical assistance in dying. If I am not mistaken, palliative care involves the totality of supportive care approaching death. A patient could therefore calmly and confidently opt for medical assistance in dying. As Ms. Campbell said earlier, medical assistance in dying must not be regarded as a failure of palliative care. The two principles must not be seen as conflicting. Is that your opinion?

**Dr. Nathalie Zan:** As we approach death, we might be satisfied with palliative care alone, or we might find ourselves in a situation where our suffering is too intense, in spite of that palliative care. Suffering can sometimes be absolutely intolerable. That is the real reason for having access to medical assistance in dying. It is used when needed. The option is there. Some patients may be getting along perfectly normally in palliative care and not expect to request medical assistance in dying, but given the deterioration in their condition, they decide to choose that option.

**Mr. Luc Thériault:** In palliative care and end-of-life care, pain control methods can bring about death in the long term. The patient will die not necessarily of complications associated with their cancer, for example, but rather of a heart attack caused by a last dose of pain relief medication. Because there is no resuscitation protocol, death then occurs.

Does this mean that we could say that palliative care is an action that leads more slowly, bit by bit, to death?

[*English*]

**The Joint Chair (Hon. Yonah Martin):** Be very brief, Dr. Zan.

[*Translation*]

**Dr. Nathalie Zan:** Yes, the disease can be the cause of death, but there are also dehydration and withholding food. The important thing is to relieve all this suffering. The objective of palliative care is to relieve the suffering associated with the process of dying.

[*English*]

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

Next we will have Mr. MacGregor.

You have the floor for five minutes.

**Mr. Alistair MacGregor (Cowichan—Malahat—Langford, NDP):** Thank you very much, Madam Chair, and thank you to all our witnesses for appearing before the committee.

Mr. Ross, I'd like to start with you. I think in your opening statement you underlined the complex relationship between the courts and Parliament.

Throughout our study, section 7 charter rights have come up frequently, but mostly in the case of people having the right to determine what kind of care they want and what kind of decisions they want over their own body. I actually found it interesting that you brought it up from a different perspective, underlining the first part of section 7, the right to life, and that this might be compromised because someone is not getting the full range of access to services, especially in palliative care.

To your knowledge, is there any individual or group of lawyers in Canada bringing a charter challenge from that perspective at this moment?

• (0920)

**Mr. Derek Ross:** I believe there was a statement of claim issued by Roger Foley. I would have to go back and check where that litigation currently stands.

At this point, this issue hasn't been explicitly addressed by the courts in a written decision, but we do feel there are charter issues engaged here. Just to play that out, you can look at some of what the Supreme Court of Canada has said about the right to life. In Chaoulli, the court said the right to life is engaged where evidence shows that the “lack of timely health care can result in death”. In that case, the court also said, “delays in obtaining medical treatment which affect patients physically and psychologically trigger the protection of s. 7”, which is for security of the person. In Carter, the court said, “The right to life is engaged where the law or state action imposes...an increased risk of death on a person, either directly or indirectly.”

If we have a regime where certain basic health care supports are needed by a patient but are not available, where death is effectively being offered as the only accessible solution and where the government has not acted as it should in securing adequate supports that would otherwise lead a person not to seek death, then I think section 7 is engaged.

**Mr. Alistair MacGregor:** I'm sorry to interrupt, but my time is running out. I do want to continue with you, though.

You were talking about the legal distinction between medical assistance in dying and palliative care. In actual medical settings, we have patients who are often in palliative care and make the decision that they want to transition to medical assistance in dying. Often it's happening in the same place. While I agree that you have the legal distinction, practically it's often happening in the same place. For lack of better purposes, it is a part of continuum of care in the practical setting.

We just heard from Dr. Zan that some patients, when they make a choice to transition from palliative care to MAID, have had to transition to a different facility because services aren't offered. In your opinion, how do we balance the rights of the institution providing the care with the rights of the patient to have that continuum of care and not have the end of life interrupted in such a severe way?

Let's say you've gone through palliative care and feel like the treatments aren't working anymore, and you don't feel like you need to stay on this earth anymore but your decision to go into medical assistance in dying means you're going to be packed up into an ambulance and transported to a different facility. How do we protect your rights versus the kind of care you're receiving?

**Mr. Derek Ross:** These are all questions that need to be looked at. At the end of the day, even though both MAID and palliative care may be provided to the same patient, I think it is important that a person who is seeking MAID continues to be offered palliative care. That's absolutely crucial. We shouldn't look at it as a binary where either you choose palliative care or you choose MAID, and if you choose MAID there's no palliative care available to you. I think Dr. Zan's testimony on that point—that this is still emphasized—is really important. Yes, there is a legal distinction, but that doesn't mean someone seeking MAID should not be offered all of these palliative care supports.

I think the challenge though—even in the example you provided—is that often palliative care is only being provided at a very late stage, even after a point that a person is seeking MAID or in the final two weeks of their life. As we've seen in some of the Health

Canada reports, the evidence that's been heard is that it's not soon enough. Giving only two weeks of palliative care is not going to begin to address some of these deeper issues.

Even before we get to the dilemma you've just identified, it's important that there be early interventions, early referrals and early awareness of palliative care so that it's being provided over a long term. Then we don't get to this point where someone is in the possible dilemma of feeling like they only have a couple weeks of palliative care and then have to be transferred.

I think it's really something that requires a proactive, pre-emptive approach. It has to take place at a very high societal level for us to be prioritizing it.

• (0925)

**The Joint Chair (Hon. Yonah Martin):** I was listening to the answer. We did go a bit over the five minutes, but thank you.

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

**The Joint Chair (Hon. Yonah Martin):** I'm going to now turn it over to my co-chair and we will have questions from the senators.

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

We'll now have senators' questions, beginning with Senator Mégie for the next three minutes.

[Translation]

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

I want to thank the witnesses for being with us today.

My first question is for Ms. Campbell.

In your opening remarks, you talked about the fact that some people are less likely to be referred for palliative care. Can you give us some examples where, given the patient's health, the doctors or health professionals are less likely to refer patients care for palliative care?

[English]

**Ms. Julie Campbell:** Thanks for the question.

Patients with chronic life-limiting conditions, such as ALS and COPD, are less likely to be identified. Even less likely to be identified are the frail elderly or patients with dementia.

It is really important to see patients for the whole of who they are and to see all of the complexities of their conditions added together to consider where they are on the trajectory of life and to identify early when we can intervene with palliative care to give them the best quality of life.

[Translation]

**Hon. Marie-Françoise Mégie:** Thank you, Ms. Campbell.

My second question is for Dr. Zan.

If I understood correctly, you have worked in geriatrics, but you are now also working in palliative care and you have administered medical assistance in dying.

In light of the definitions and criteria, I would like you to help us better understand what the difference is between continuous palliative sedation and medical assistance in dying.

**Dr. Nathalie Zan:** Are you talking about the eligibility criteria?

**Hon. Marie-Françoise Mégie:** Yes.

In fact, what is the role of each of these types of care? Things often get confused: people think that offering continuous palliative sedation to someone in palliative care kind of amounts to administering medical assistance in dying.

I would like you to clarify that.

**Dr. Nathalie Zan:** That is entirely different.

Personally, I have never administered palliative sedation.

In general, medical assistance in dying is a rapid process that is meant for patients who are fully aware of their situation and their choice. Palliative sedation can be a patient's choice too, but it can also be administered when the patient is no longer conscious. Sometimes it is a family's choice.

I have administered medical assistance in dying much more. Ending their life this way is truly a patient's choice. Administering this care is entirely different.

I imagine that palliative sedation can be administered more in a context of palliative care. When the medication becomes insufficient, palliative sedation can be the next step in palliative care.

In the context of medical assistance in dying, at least in my experience, I imagine that the two practices could be interchangeable. The fact remains that the patient consciously chooses to receive medical assistance in dying. It is a specific moment during which the care is administered.

That is how I would summarize the question, although I have never administered palliative sedation.

● (0930)

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

I will now give Senator Dalphond the floor for three minutes.

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

My question is for Dr. Zan.

Statistics show that at least 82% of people who receive medical assistance in dying were receiving palliative care before that.

In your experience, are there people who are receiving palliative care and request medical assistance in dying who decide not to act on their request, or does medical assistance in dying always end in it being administered at some point?

When they decide to receive medical assistance in dying, is it because they feel that the quality of the palliative care is insufficient or because they want to choose the end of their life themselves

rather than waiting for the family to choose continuous palliative sedation for them?

**Dr. Nathalie Zan:** In my experience, in a majority of cases, patients who had received palliative care and wanted to receive medical assistance in dying received both. It was a decision that came after consideration.

A patient who is in the terminal phase, for example, can be admitted to palliative care and receive care as their condition changes. Often, these people are already considering medical assistance in dying. We then discuss that possibility together, at the same time as they are receiving the usual palliative care. Sometimes, these people change their mind, but in a large majority of cases they do not change their mind. The large majority of people who maintain the wish to receive medical assistance in dying do receive that care, even if they are simultaneously receiving palliative care.

**Hon. Pierre Dalphond:** Some witnesses have said they are afraid that people receiving palliative care ask for medical assistance in dying at a time when they are depressed, that their existential problems are not addressed and they are given medical assistance in dying.

When you do the assessment, do you take that into account?

**Dr. Nathalie Zan:** We always take it into account. There may be situations like that. However, in my experience in palliative care, it is a request that has been thought about, often for a long time. So it is a process that takes shape in the person's mind.

Have I encountered situations in the past when the person was unable to receive palliative care? Yes, of course, that has happened. However, as you say, in a majority of cases, in about 80%, the patients receive both types of care, and that is what we want: we truly want everyone to have access to both options.

Some people may have made the decision after thinking about it for several years, while others arrive at this conclusion because they are suffering too badly in spite of palliative care. I would remind you that suffering can be psychological, also. Waiting for death is psychologically very difficult for some people, so they decide to turn to palliative care. While the usual palliative care relieves pain and symptoms, existential suffering is more difficult to relieve, even when the palliative care is optimal.

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

We will now continue with Senator Martin.

[English]

Senator Martin, you have three minutes.

● (0935)

**The Joint Chair (Hon. Yonah Martin):** Chair, Senator Wallin is also online.

**The Joint Chair (Hon. Marc Garneau):** Okay. I didn't pick that up, so—

**Hon. Pamela Wallin (Senator, Saskatchewan, CSG):** I've come late, so I'll participate in the next section. Thank you.

**The Joint Chair (Hon. Yonah Martin):** Okay. Thank you. I thought your camera had just come on.

Thank you, Mr. Chair, and thank you to all of our witnesses.

My question is for Mr. Ross.

Mr. Ross, for the government to improve access to palliative care, does palliative care need to be recognized as an essential service in the same way that MAID is? What would the federal government's role be in that?

**Mr. Derek Ross:** I think it is so important that to the extent that there are gaps.... We understand there are gaps, especially between urban and rural regions, for example. There are some questions about when palliative care is considered an insured service versus an extended service, and I think clarity is needed on those questions to ensure uniformity and consistency in the provision of palliative care. That might be something that needs to be done in conjunction with the provinces, but there's still a role for the federal government to play in ensuring that there is consistency.

This goes to Senator Dalphond's question about those who change their mind because of palliative care. The third annual report that we have from Health Canada provides some information in that regard. It tells us about the reasons why individuals withdrew their request for MAID. It specifically tells us that in 38.5% of cases where individuals withdrew their request for MAID, it was because palliative care measures were sufficient. By my calculation, that's 88 people in 2021 alone who withdrew their request for MAID because palliative care measures were sufficient. How much more would people be informed by broader and wider access to palliative care across the country, where we see these discrepancies?

Another area of focus that the federal government can emphasize is research. They can fund research and get more information, data and standards about these issues. They can work with the provinces to improve training for medical students and other health care professionals so that there's greater awareness of what palliative care does, especially, as I mentioned, in the area of pediatrics, where many regions don't have specialized pediatric palliative care. It's so crucial, I think, for this to be emphasized moving forward.

**The Joint Chair (Hon. Yonah Martin):** I think you've touched on my second question: More broadly, what should the federal government do to improve access to care?

After hearing about the specialized care, I see that's quite concerning too. Do we have enough specialists to address the very specialized palliative care that would need to be offered?

**Mr. Derek Ross:** Yes, that's exactly right.

Again, I think a lot of people, me included, have a lot of misconceptions and misunderstandings about what palliative care is. I think a lot of people assume that it's just this last-minute attempt to help people. It's something that really does a lot for a lot of people at various stages of life with various conditions.

There needs to be greater awareness of this as an option so that individuals know, especially those who are struggling with some of these decisions, that they have options available to them other than MAID. For those options to be realized, it's crucial that we have

funding, infrastructure, training and public awareness so that this is emphasized and prioritized. Ultimately, all of us involved in the discussions on these issues have different approaches and different ideas, but we all share a commitment to wanting to help people who are suffering.

That's what everyone here wants to do. How do we best support individuals who are suffering? We need to ensure that we give them the support to live with dignity and that the option is available to them. I think that's where this emphasis on palliative care is especially important.

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

This brings our panel to a close. I'd like to thank Ms. Julie Campbell, Dr. Nathalie Zan and Derek Ross from the Christian Legal Fellowship for appearing this morning at an early hour to provide their views and answer our questions. We very much appreciate that in the context of our review and examination of palliative care and where medical assistance in dying might fit in with that.

With that, we will suspend briefly and prepare for our second panel. Thank you.

• (0940) \_\_\_\_\_ (Pause) \_\_\_\_\_

• (0945)

**The Joint Chair (Hon. Marc Garneau):** Welcome to the second panel and welcome to our witnesses in particular.

I have just a few little reminders. Before speaking, please wait until I recognize you by name. All comments should be addressed through the joint chairs. When speaking, please speak slowly and clearly. This will help the interpreters. Interpretation is available in three options: floor, English and French. When you're not speaking, please mute your microphone.

With that, I would like to welcome our witnesses for panel two. We are here to discuss the issue of advance requests primarily.

[*Translation*]

We welcome Serge Gauthier, emeritus professor, as an individual, who is joining us by videoconference.

[*English*]

We welcome Nancy Guillemette, member of the Government of Quebec, also by video conference.

Pending his arrival, hopefully soon, we'll have Dr. Sandy Buchman, chair and medical director of the Freeman Centre for the Advancement of Palliative Care at the North York General Hospital and past president of the Canadian Medical Association.

Thank you for joining us.

We will begin with opening remarks.

[*Translation*]

We will begin with Dr. Gauthier, followed by Ms. Guillemette and, we hope, Dr. Buchman, who should be joining us shortly.

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

**Dr. Serge Gauthier (Emeritus Professor, As an Individual):** Thank you, Mr. Chair.

Good morning, everyone.

I am a neurologist specialized in the diagnosis and care of persons living with dementia, Alzheimer's disease in particular.

Over the years, many persons without symptoms but at risk of dementia in the future because of their family history, or with mild symptoms, spontaneously asked during office visits whether they can write advance requests for medical assistance in dying if they reach a certain stage of their condition. Some even signed a document, with their spouse, written with the help of their family, knowing that the document was not yet valid. Some persons even said that if they did not have the option of giving advance directives in order to receive medical assistance in dying, at a predetermined stage of a disease like dementia, they would seriously think of suicide at the time they received that diagnosis. I would add that there is medical literature on this subject. There is thus a real need expressed by a segment of the population that is openly discussing this with family members.

The difficulty I foresee is not so much the fact that these persons have to write a document with the help of the family or a notary, for example. Rather, it is the clarification of which stages of dementia might create problems when their advance choice is put into effect.

Allow me to explain in greater detail.

There are very advanced stages in Alzheimer's disease. No one wants to live until the very severe stage, defined as absence of verbal communication and independent ambulation, double incontinence, and very high risk of aspiration pneumonia. This is a terminal stage of dementia in which death is expected within 12 months.

On the other hand, if a person expressed a desire to receive medical assistance in dying before that terminal stage, but after being declared incompetent, in other words, at a moderate to severe stage of dementia, it might be harder to obtain a consensus between the designated representative and the clinical team once the disease has progressed to the preselected stage.

Finally, after receiving a diagnosis of Alzheimer's disease, a person might decide to receive medical assistance in dying while still competent, thus in a mild stage of their condition. At that stage, I believe the person's choice is clear and valid.

To start the dialogue with the committee, I ask it to consider the stages of the disease in their deliberations and help people to plan for carrying out their choice at the appropriate time.

Thank you for your interest in this important issue.

• (0950)

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

Ms. Guillemette will now have the floor for five minutes.

**Mrs. Nancy Guillemette (Member for Roberval, Government of Quebec):** Mr. Chair, Madam Chair, vice-chairs, members of the Special Joint Committee on Medical Assistance in Dying, thank you for allowing me time to speak today.

My name is Nancy Guillemette. I am a Coalition avenir Québec MNA and I represent the electoral district of Roberval. I chaired the proceedings of the Select Committee on the Evolution of the Act respecting end-of-life care.

As you undoubtedly know, the Act respecting end-of-life care came into force in Quebec in 2015. Since then, the Commission sur les soins de fin de vie has monitored requests for medical assistance in dying. Quebec society is thus able to monitor changes in the number of deaths and have a realistic picture of the situation, and make sure that the requirements for administering medical assistance in dying are met. We can also assess and better understand the suffering of people who obtain medical assistance in dying.

In order for Quebec to continue to progress in this area, the Select Committee on the Evolution of the Act respecting end-of-life care, the transpartisan committee that I chaired, was created in March 2021. The select committee's mandate was to examine the issues related to extending medical assistance in dying to persons who are incapable of caring for themselves and those who are suffering from mental disorders.

In the course of our work, which represented over 200 hours of consultations and discussions, we met nearly 80 persons and organizations. There was also an online consultation that allowed Quebecers to express their views. Our work was guided by three broad questions. First, may persons who are not capable of consenting to care obtain medical assistance in dying, in particular by making an advance directive? Second, should persons whose only medical condition is a mental disorder have access to medical assistance in dying? If so, what criteria should apply to extending access to medical assistance in dying to such persons?

The select committee submitted its report on December 8, 2021. It is important to note that the 11 recommendations in the report were made unanimously. They reflect how the public's perceptions of medical assistance in dying in Quebec have evolved.

The members of the select committee recommended that persons with a serious and incurable illness leading to incapacity be able to make an advance request for medical assistance in dying. The recommendations also sought to guide and circumscribe the concept of free and informed decision, clarify the role of the trusted person who would communicate the sick person's request when the time came, and guide the intervention and support the doctor.

However, the select committee members noted that there was no social consensus concerning the incurable and irreversible nature of mental disorders. We therefore recommended that access to medical assistance in dying not be expanded to persons whose only medical condition is a mental disorder. The select committee members were of the opinion that the subject is much too important not to obtain social consensus.

The Government of Quebec acted on the select committee's report by introducing a bill, in May 2022. The bill proposes that persons who have a diagnosis of a serious and incurable illness leading to incapacity, and persons with a neuromotor disability, be given medical assistance in dying. The bill refers to neuromotor disabilities, but, since the select committee did not consider that subject, I will not address it today.

Unfortunately, parliamentarians did not have time to complete the parliamentary committee's work before the election was called in Quebec. The bill is therefore to be reintroduced in the new legislature, the one that is starting now.

Quebec has always been a leader in the vanguard of medical assistance in dying and end-of-life care. We want to continue to progress, but we want there to be a consensus among the Quebec public.

Thank you for your attention.

I am now prepared to answer your questions.

• (0955)

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

The clerk confirms that Dr. Buchman is still not present at the meeting. Let us hope he will join us shortly.

I will now give the floor to Senator Martin, who is co-chairing the meeting with me.

[*English*]

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

Thank you to both of our witnesses this morning. Your testimony will take us into this next questioning period to draw out more insights and what you have to offer us.

Our first five minutes will be for Madame Vien.

Madame Vien, you have the floor.

[*Translation*]

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

Good morning, everyone.

Welcome, Ms. Guillemette. Congratulations on your election in Roberval electoral district. We followed this election with great interest, as you can imagine.

Because my time is short, I am going to get directly to the point.

Obviously, you are correct to say that Quebec leads the way on a number of issues, including end-of-life care. I was in the govern-

ment at the time, when the Act respecting end-of-life care was enacted.

[*English*]

**The Joint Chair (Hon. Yonah Martin):** Excuse me, Madame Vien, but Dr. Buchman is now here. Would you like to hear the witness first? That might be helpful.

[*Translation*]

**Mrs. Dominique Vien:** Yes, go ahead.

**The Joint Chair (Hon. Yonah Martin):** Right, thank you.

[*English*]

Dr. Buchman, thank you for joining us. I hope you're ready to go into your testimony. You will have five minutes.

**Dr. Sandy Buchman (Chair and Medical Director, Freeman Centre for the Advancement of Palliative Care, North York General Hospital, and Past President, Canadian Medical Association, As an Individual):** My apologies. There were serious technical problems, but I was on the whole time.

Good morning and thank you for asking me to appear before you today.

My name is Sandy Buchman. I'm a palliative care physician and the chair and medical director of the Freeman Centre for the Advancement of Palliative Care at North York General Hospital in Toronto. I'm also the former president of the Canadian Medical Association. I spend much of my time providing home-based palliative care, and for a number of years I have provided care to those experiencing homelessness. I am also a MAID assessor and provider.

My comments today may be appreciated through the lens of three important areas for both palliative care and MAID: access, equity and compassion. I will also share some of my concerns regarding current and future states of practising palliative care in MAID.

In Canada, we have several exemplary palliative care frameworks, such as Health Canada's 2018 framework on palliative care in Canada, as well as many province-specific documents. They all recommend innovative and cost-effective ways to improve equitable access and save vast amounts of money in adopting a palliative approach to care when indicated. However, despite dedicated professionals and volunteers having worked so hard for so many years to create these reports, most of these ideas and plans never see the light of day—certainly not in the world in which I work. Why is that? We rarely see the dollars to fund these evidence-based recommendations.

Let me share a personal, concrete example. About seven years ago, I co-founded a new hospice residence in our community of North York called Neshama Hospice. Best practice suggests 10 to 12 end-of-life beds for 100,000 population. In North York, we have a population of about a million and should therefore have 100 to 120 beds. I will tell you that there are zero palliative care unit beds and zero hospice residence beds in our area. We have raised \$18 million so far for our new hospice, but now with inflation, several million more have to be raised. We are to receive \$2 million in provincial government funding, which will amount to less than 10% of our costs. Operational dollars will not make up even 50% of our costs. The majority of Canada's patients at end of life—up to 70% in many areas—die expensively in hospital because of inadequate funding of community supports like hospice or home care.

Why is it that essential, high-quality, appropriate and very cost-effective palliative care is mostly charitable? If we want to improve access, equity and compassionate care for Canadians, I believe the federal government has an important role to play in setting national standards and providing funding, through the Canada health transfer, to be directed to palliative and hospice care, enacting its own framework. It's beyond time to walk the talk.

The average expected life span for those entering long-term care is only 18 months. If that does not require a palliative approach to care, I'm not sure what does, yet very few long-term care facilities practise such an approach. This often results in many of our elderly and frail citizens being sent to emergency rooms when their clinical conditions worsen. They are admitted to an acute care bed in hospital where they may remain for weeks or months, not being able to return to their home facility as they decondition so quickly.

A recent C.D. Howe report showed that about 40% of these patients have less than a 90-day prognosis. For a moment, please recognize that if we had more options for care in the community, we could do so much more to relieve our collapsing health care system. This alone would make a significant dent in freeing up acute care beds, and would impact the current capacity challenges and wait times in our hospital system.

Recently, stories have appeared in the media about people with a chronic disease or disability who lack necessary social supports and resources to live a quality of life they deem worth living. Thus, they request MAID, usually through track two. I have every sympathy for these individuals and believe that many are suffering intolerably. Although I've heard about a few of these tragic cases, in reality they are also relatively few in number. Indeed, many say they don't really want MAID but would rather die than continue to live in their impoverished circumstances. This is the basis of their intolerable suffering.

Critics of MAID legislation cite that it is easier to access MAID than adequate health, social and financial supports, and indeed that may be true. Their proposed solution is to toughen up our MAID laws. However, the problem is not the MAID legislation per se, as a person still has to meet all the eligibility criteria. I believe a lack of adequate and appropriate housing, financial supports, access to timely and consistent addiction, mental health and rehabilitation services and access to palliative care are really at the root of their requests. Inadequate and insufficient health, social and financial supports drive death. They do not drive MAID. If we want to pre-

vent needless deaths, let's adequately fund social support and health services. More people will live longer and better lives.

• (1000)

Finally, there is one issue I'd like to highlight with respect to current MAID legislation.

The waiver of final consent, meant to ensure that an eligible patient's wishes for MAID are honoured if they lose capacity, has been an extremely valuable amendment to our MAID laws, but it may also have a flaw. There have been anecdotal reports of this waiver being applied to procedures months later, and even two to three years into the future, after the patient has been found eligible but may not want MAID just yet. It has become a de facto kind of advance consent, in my humble opinion. This was not the intention of this amendment, of course. I bring it to the committee's attention as I think it needs to be explored and studied further.

Thank you for this opportunity to appear before you today to share my perspectives on palliative care and MAID.

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

I will return to Madame Vén. I'll restart so that you have five minutes.

[*Translation*]

**Mrs. Dominique Vén:** Ms. Guillemette, should the Government of Canada move forward regarding advance requests for medical assistance in dying?

**Mrs. Nancy Guillemette:** We are preparing to reintroduce our bill, which we hope to have passed in Quebec. The conclusions in the report we produced at the Select Committee on the Evolution of the Act respecting end-of-life care, which I chaired, were unanimous. We are therefore hopeful that Quebec will pass this bill.

We have always led the way, in Quebec. We hope not to be at odds with Canada, but I will leave it to the federal government to do its job.

**Mrs. Dominique Vén:** You used the word that sums up the discussion. If Quebec did move forward in this regard, but not the federal government, how could we live in two parallel worlds, legally speaking?

What is your opinion on that?

**Mrs. Nancy Guillemette:** We shall see how the respective governments of Quebec and Canada handle the situation at that time. For the moment, we too have no law. It is just a bill.

• (1005)

**Mrs. Dominique Vien:** Right.

You introduced the bill in May, I believe, but you say you did not have time to move forward.

Mr. Dubé, who has been reappointed as minister, is to reintroduce the bill.

Have you given yourselves a deadline for passing the bill?

**Mrs. Nancy Guillemette:** No, there isn't one.

**Mrs. Dominique Vien:** Earlier, you referred to neurological disabilities. They were included in the bill, but ultimately they were removed by Mr. Dubé.

Do you want to add that aspect back, since you will have more time to discuss it?

**Mrs. Nancy Guillemette:** In fact, the study of neuromotor disabilities was not part of our committee's mandate, so we did not study that issue. That is why the minister removed it from the legislation. I do not know whether there will be other proceedings that will make it possible to add that aspect back to the bill. We have not yet introduced the new bill.

The previous bill was introduced in May, and when we saw that we would not have time to pass it before the end of the parliamentary session, all parties agreed to bring it back. Everyone agreed that the bill had to be brought back quickly.

We do not know whether it will take the same form or whether amendments will be made to it. We will have to wait for the bill to be introduced to know.

**Mrs. Dominique Vien:** Thank you, Ms. Guillemette.

At the Special Joint Committee on Medical Assistance in Dying, we also wonder about requests for medical assistance in dying when the only condition cited is a mental disorder. In Quebec, you decided not to move forward on that point, so I feel obliged to take the opportunity your presence here offers, to ask you some questions about that.

You said that you decided not to move forward because you had not felt any consensus among the public.

How did you measure that, apart from the fact that you conducted a survey and consulted 80 groups in the medical field?

Why did you not act on that, and what would you do if we were to move in that direction?

**Mrs. Nancy Guillemette:** Regarding the technical aspect, I would note that we did consult 80 groups, organizations of health professionals and doctors. As we made clear, mental health is too important a subject for there not to be consensus in that regard. We did not perceive that there was a social consensus on moving in that direction.

At present, it is too difficult to determine whether there is an irreversible or incurable illness. However, the subject is really important. We decided that we would not make recommendations in that regard for the moment, and that we would see whether, in future, a new committee would study only the question of requests for medi-

cal assistance in dying on the sole ground of a mental health disorder. Given the data we had and the lack of social consensus, we believed it was too difficult to expand medical assistance in dying to include mental disorders as the sole ground relied on.

A person who has a mental disorder and also suffers from another illness may still be eligible for medical assistance in dying. The person's request will not necessarily be refused because they have a mental health disorder. It will be refused if the sole ground for the request is a mental health disorder.

On the subject of the legislation and consistency between the federal and provincial positions, we shall see how things turn out on the federal side. There will certainly be adjustments.

[*English*]

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

Next we have Mr. Arseneault. You will have the floor for five minutes.

[*Translation*]

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

I would like to thank our witnesses. It is always nice to hear your testimony, which helps us a lot in moving ahead on this issue.

I would first like to address Dr. Gauthier.

Dr. Gauthier, I want to thank you for your presentation. It is the shortest one I have heard since I began sitting on this committee, and yet it was full of information. As a legislator, I find your comments particularly useful in connection with advance requests for medical assistance in dying, a subject that we will be addressing with this second group of witnesses.

If I understood correctly, you support the idea of opening up medical assistance in dying to advance requests. You specialize in Alzheimer disease. You talked about the various stages that can be determined and based on which medical assistance in dying could be given.

My question is twofold.

At what point do you think a person can make an advance request? You talked about patients or people you know who are afraid of being struck by that disease because members of their family suffer from it.

To summarize, do you support advance requests by persons who do not have symptoms of Alzheimer disease?

• (1010)

**Dr. Serge Gauthier:** At present, the consensus is that a diagnosis must already have been made. With that said, it could be a very early stage of the disease. A person could not request medical assistance in dying based on a fear of eventually having a certain disease.

On the other hand, it is possible to document their preferences in writing, even if no disease has yet been declared. We are already doing that when we complete a protection mandate to facilitate our decisions in the event of incapacity.

A person can use a special clause to tell their designated representative whether or not they want extraordinary measures to be performed in the event of a stroke, for example, if there is no hope of recovery. Could we include medical assistance in dying in those wishes? I don't know.

To answer your question specifically, I will say that we have to wait for a precise diagnosis.

**Mr. René Arseneault:** Suppose that I receive a precise diagnosis of Alzheimer disease or a form of dementia and I sign a document stating my desire to receive medical assistance in dying once the disease has reached a particular stage.

Can you define what the determining factor would be, for a legislator, in order for a stage to be recognized by lawyers and by the courts and doctors?

That is where the line has to be drawn.

**Dr. Serge Gauthier:** That is a very good question. I have tried to make it a bit operational, for the committee's needs.

At the first onset of Alzheimer disease or some type of dementia, people are competent. That is the time for them to put their affairs in order. That period may last one year or two years or three years. As long as they have not been declared incapable, they may express their wishes and make a request at that point for medical assistance in dying if they want it and they are not suffering from depression, in particular.

At the other extreme, there is the terminal phase, when there is really no hope that the persons will live more than a certain number of months. I believe that everyone states in their wishes that they do not want to continue to live if they are in the terminal phase of a neurological disease.

It is the intermediate stage that could present a problem. A person has been declared incapable but still enjoys a degree of mobility and still interacts with the environment to a certain point. That period lasts an average of two to three years. The stage of incapacity has been recognized, but the person has not yet reached the terminal phase in a recognized way.

**Mr. René Arseneault:** Right.

I'm sorry to interrupt you, but I do not have a lot of time left.

What is the stage of incapacity recognized in your profession?

**Dr. Serge Gauthier:** It is when a judge has agreed to homologate a mandate in the case of incapacity based on a medical assessment report, supported by a psychosocial assessment report. There is no change being made to the present legislation for homologating a mandate in the case of incapacity.

**Mr. René Arseneault:** Perfect.

Ms. Guillemette—

[*English*]

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

[*Translation*]

**Mr. René Arseneault:** Right. Thank you.

Ms. Guillemette, do you have anything to add in relation to those comments on advance requests?

**Mrs. Nancy Guillemette:** What is important is individual self-determination.

We spent a lot of time discussing individual self-determination and, as Dr. Gauthier was saying, it is possible at present to give advance directives. However, an advance directive for medical assistance in dying is another thing.

I think that falls on a continuum of palliative care. A person can be receiving palliative care and request medical assistance in dying. Here in Quebec, we have...

**Mr. René Arseneault:** I'm sorry, but my speaking time is up.

Thank you both very much.

**Mrs. Nancy Guillemette:** Thank you.

[*English*]

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

Next we will go to Monsieur Thériault. You have five minutes.

[*Translation*]

**Mr. Luc Thériault:** Madam Chair, before the countdown on my speaking time starts, I have a point of order.

I would like Ms. Guillemette to clarify something for me.

In the notice of meeting, it says that she represents the Government of Quebec. I would simply like to know whether she is here as the chair of the Select Committee on the Evolution of the Act respecting end-of-life care or, in fact, as a representative of the Government of Quebec, because that changes everything.

If we want to hear a representative of the Government of Quebec who is authorized for that purpose, we will do that later. If I understand correctly, she is here today as a representative of the Government of Quebec.

Can we clarify that now? We should perhaps have done that before the meeting. I just want to know whether that is indeed the case.

• (1015)

[*English*]

**The Joint Chair (Hon. Yonah Martin):** Go ahead, Madame Guillemette.

[*Translation*]

**Mrs. Nancy Guillemette:** I was mandated to appear here as a representative of the Government of Quebec. However, I was also the chair of the Select Committee on the Evolution of the Act respecting end-of-life care.

**Mr. Luc Thériault:** Right. Thank you very much.

You understand, Ms. Guillemette, that I make a distinction between a government and the legislative process, which you participated in and which you also chaired.

Dr. Gauthier, with respect to Bill C-7, I had asked you earlier at what point, and up to what point, a patient could be considered to be capable of making an advance request. My colleague also asked you the question. At that time, you told me about stages 3 and 4.

Is your answer the same now?

**Dr. Serge Gauthier:** Thank you for the question.

Actually, we avoid using numbers, because the nomenclature relating to the stages of Alzheimer disease is in the process of being changed. There are now six, three of which precede the stage of dementia. For that reason, I suggest that you not use numbers at this time.

The most important thing is to use the tools already in place. A person is capable up to the time when they are declared incapable by the court, based on a medical assessment report and a psychosocial assessment report, and...

**Mr. Luc Thériault:** Right.

I followed the work done on the subject in Quebec City, and a lot of questions turned on what was called "contemporary suffering", "happy dementia".

What do you think about that?

With respect to the condition of the brain, I imagine that when a person has reached those stages, it can't be very easy to deal with it. It is referred to as an irreversible condition.

**Dr. Serge Gauthier:** Thank you for the question.

That is correct. In order for committee members to clearly understand what we are talking about, I would point out that this is a stage of dementia where people are generally already incapable. They are then living in a protected environment which is ordinarily an institution, in our culture. In addition, their interaction with their environment seems to be happy.

The purpose of my comments is this. If the person had chosen prior to that precise stage to receive medical assistance in dying, there would be no hesitation on the part of the trusted person who had been designated to represent them, that is, the third person, or on the part of the clinical team.

**Mr. Luc Thériault:** So there would be no questions. On the other hand, for people who are wondering, could we say that essentially, everything depends on the third person? At some point, that person has to ask the care team to start the assessment process. That does not mean that the care team is necessarily going to agree and proceed with the assessment, but it all depends on the examination process being initiated at the request of the third person.

However, if the third person, as third person, is not concerned about the patient's condition because they personally believe that the patient may still be experiencing happy interaction, at that time, that is not a problem.

**Dr. Serge Gauthier:** That is correct.

**Mr. Luc Thériault:** It is really quite important to emphasize the third person. In this process, which seems to me to be fundamental, it will be the solemn occasion when all these arrangements will be made.

Do you agree with me on that?

**Dr. Serge Gauthier:** I agree on that.

As a recommendation to the committee and to the provincial committees that will have to make it all operational later, I would say that the importance of informing the third person or the caregiver of the stages of the disease must be stressed.

The third person or caregiver, together with the person who has the disease, if possible, has to decide the stage of the disease at which they both agree that when the time comes, the third person will be comfortable saying that it is the appropriate time, that it is the time the person who has the disease would have chosen for receiving medical assistance in dying.

• (1020)

**Mr. Luc Thériault:** A person could say that they would like medical assistance in dying to be given when they have reached the severe stage. That can also be possible.

Is that correct?

**Dr. Serge Gauthier:** That is correct.

I think it is even easier, for the reasons I have mentioned, when death is foreseeable within the next year, for example.

**Mr. Luc Thériault:** As a final point, I imagine that your patients want to live as long as possible. The reason we are asking about advance requests is that those people want to enjoy life as long as possible up to the time they cross the threshold of the intolerable. It therefore varies based on the individual's request.

Am I correct?

**Dr. Serge Gauthier:** That is entirely correct.

**Mr. Luc Thériault:** At the severe stage of the disease, you told us, most of the time the person can survive for a year, two years, a few months.

**Dr. Serge Gauthier:** That is correct.

When aspiration pneumonia occurs, ordinarily death occurs within the next six or 12 months.

**Mr. Luc Thériault:** That is if...

[English]

**The Joint Chair (Hon. Yonah Martin):** Monsieur Thériault, there is no more time. Thank you very much.

[Translation]

**Mr. Luc Thériault:** That is unfortunate.

[English]

**The Joint Chair (Hon. Yonah Martin):** We have Mr. MacGregor now, for five minutes.

**Mr. Alistair MacGregor:** Thank you, Madam Joint Chair, and thank you to our witnesses for appearing before our committee.

Dr. Buchman, I would like to direct my questions to you. In your opening statement you went to lengths to explain the state of palliative care in Canada and the trouble you've been having in the York Region with getting a hospice. I'm sorry for the struggles you've had.

I think you also mentioned that for long-term care, the average lifespan was 18 months, and that the transfer of patients from long-term care to hospitals is a very difficult and costly process and is often quite detrimental to the quality of life of the patient.

There has been a lot of discussion in the federal sphere, especially following the very evident problems we saw at long-term care during the pandemic, about implementing something like a long-term care act or a long-term care strategy to ensure that we have a set of standards no matter where a Canadian resides.

In the context of your opening remarks, and with palliative care in there as well, what do you think a long-term care strategy should include, at a bare minimum?

**Dr. Sandy Buchman:** Thank you for the question.

The long-term care strategy should include, at a bare minimum, obviously, national standards for care right across the country so that you won't get a deficiency of care in one region versus another. At this point in time, there is. For example, we did see in the pandemic that for-profit long-term care facilities did much worse than not-for-profit long-term care facilities in terms of the number of deaths that occurred within the facilities. We need bare-minimum national standards.

Some of those national standards should include hours of nursing care and personal support care, a minimum but optimal number of hours that each resident should get. The standards should include architecture that includes private rooms and all the latest standards for prevention of infectious disease. They should include vastly increased supports for home care. Rather than putting billions of dollars into bricks and mortar, we need to establish the focus on home care so that people who need long-term care can experience it in their own homes in an adequate way. That's where people want to be.

I think that's obviously where the greatest investment is. We need standards of home care and accessibility in all regions and jurisdictions as well.

**Mr. Alistair MacGregor:** Can I interrupt for 20 seconds? Sorry.

You were talking about the costs. Can you give the committee an example of the costs for someone who meets the end of their life in hospital? They might fall into medical distress, but they are in end-of-life care. What are these costs versus what they would be like in a hospice? I ask because the system is buckling under extreme costs right now. You did take some time to talk about the efficiencies that are present, not only in economic terms but also in the quality of care if we can invest more in hospices.

**Dr. Sandy Buchman:** I'll give you some examples. The latest that I have is old data, but I think it can be scaled up in terms of the number of dollars. It is from the Ontario Auditor General's report of December 2014.

One day in hospital for an end-of-life patient would cost \$1,100 scaled up to 2022 dollars. One day in hospital costs \$1,100. A palliative care unit in an institution would cost about \$700 a day. A hospice residence would be \$450 a day, and home care would be \$100.

In Ontario, for example, 70,000 patients die—100,000 people die, but about 70,000 die in hospital per year—and if we took, say, half that amount, say 35,000, and moved them to hospice residences, for example, there would be a saving of about \$650 per day per patient. Each patient's average length of stay is 21 days. If we took 35,000 times 21 days times \$550 for the difference, that comes into hundreds of millions of dollars.

It's the money up front that's the resistance; hence, my hospice only receives about 6% to 7% of the necessary funding to be established. I wonder why we aren't considering that to be essential health care? It makes sense. It's the quality of care that people want and deserve and it is very cost-effective.

● (1025)

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

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

Now we'll turn this over to my joint chair for questions from the senators.

**The Joint Chair (Hon. Marc Garneau):** Thank you, Senator Martin. We'll start with Senator Mégie.

[*Translation*]

The floor is yours for three minutes.

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

I would like to thank the witnesses for being here.

Good morning, Dr. Gauthier. My first question is for you.

Without using numbers to identify a particular stage of disease, could a person state in their advance request that they want to receive medical assistance in dying at the point when they are no longer able to recognize their family members, when they suffer from double incontinence, or when they have a particular disability, for example? As a professional, what do you think about that?

I have a second question for you.

After hearing your discussion with my colleague Mr. Thériault, I sense that you accept the concept of happy dementia. If the person could include that in their advance request, that would provide an additional safeguard.

Can you explain what happy dementia is? Should medical assistance in dying be given if a person is in that condition?

**Dr. Serge Gauthier:** I am going to start with the question that is easiest to answer: yes, it is possible to include a clause to that effect.

With respect to double incontinence, that is a reversible condition. For example, the person might have a urinary infection or a reversible gastric or intestinal problem. We cannot determine a stage based on a single symptom that may be temporary. Instead, there would have to be a set of symptoms that were considered to be irreversible, in order to say that a person has reached a threshold that justifies medical assistance in dying.

**Hon. Marie-Françoise Mégie:** I have just enough time to ask you a brief question, Mr. Gauthier.

Do you think we could include neurocognitive diseases in advance measures?

**Dr. Serge Gauthier:** That is a very good question. "Major neurocognitive disorder" is, in fact, the new designation used in the international classification as a synonym for "dementia". In Quebec, it is increasingly being used in clinical practice. The committee may need to include these two terms in its documents, since the expression "major neurocognitive disorder" is now used as an equivalent to "dementia" in most fields of practice.

**Hon. Marie-Françoise Mégie:** Thank you.

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

We will now continue with Senator Dalphond.

**Hon. Pierre Dalphond:** My first question is for Ms. Guillemette.

As I understood your testimony, your committee found that there was a broad social consensus in favour of advance requests for medical assistance in dying for neurocognitive disorders.

Did your committee explore the issue in order to determine what type of oversight would be required? For example, should the Criminal Code provide certain criteria, or should we instead say that advance requests are permitted where allowed by provincial legislation?

• (1030)

**Mrs. Nancy Guillemette:** On the legal aspect, I am not really competent to answer, but I would say yes. Yes, it is important to properly define the time when the designated person can report that their family member seems to have reached the stage that meets the criteria the person themselves set. This respects their right to self-determination and their pre-established choice. So the idea of happy dementia has to be properly defined, but it will also be important that there be contemporary suffering. That idea was very important in the committee's work and it has to be retained.

On the legal aspect, I will not comment, because that is not my field. At present, we are not at that point. As I said earlier, we are going to wait for the bill to be enacted in Quebec. We will also have to consider the extent to which it will be enacted. At present, there is a lot of speculation occurring.

**Hon. Pierre Dalphond:** Work has been done on advance requests at Université Laval that resulted in a very impressive report. I know the committee has not reached that stage. However, we understand that these requests are associated with the fear of losing the capacity to give consent. In Quebec, as we know, loss of capacity results in a mandate of incapacity and judicial homologation. An

entire process is set in motion. So a provision could be added saying that a third person is designated to ensure that their family member's wishes are respected, so that the entire judicial process would take place in a single step rather than multiple steps. With that said, I understand that you are not yet at that point.

**Mrs. Nancy Guillemette:** It will probably be clearly defined in the law, but as a committee, we did not go there. Because it is a bill, I cannot tell you what form it will ultimately take.

On our part, we felt it necessary that the person have established criteria when they were capable of doing so. That does not prevent their criteria from being changed at any time when they are incapable. With that said, there was an important criteria, to our minds: contemporary suffering.

**Hon. Pierre Dalphond:** [*Inaudible*] the happy dementia part.

**Mrs. Nancy Guillemette:** Let us say it is to provide better guidelines, actually. Our intention was to avoid leaving the entire weight of the decision on the shoulders of the medical profession. It is really a heavy burden for them. By providing better guidelines for it, it is more efficient for the medical profession.

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

[*English*]

We'll now go to Senator Wallin.

Senator Wallin, the floor is yours.

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

I want to come back to Ms. Guillemette on this concept of happy dementia. It troubles me greatly, because it leaves all of the decision-making to people who may not have been aware of the patients' initial witnesses or concerns, aware of what they may have stated in a document.

I know the bill is not drafted. I'm working on one in the Senate as well.

Do you think it is reasonable, and therefore reasonable for legislators, to propose the following: that a person who fears they may be a victim of a neurocognitive disease, dementia or Alzheimer's because of family or other considerations would create a list, a set of criteria, for what they want and when they want MAID to be used, and that they name third party substitute decision-makers who have agreed to that, both in advance and throughout the process, in constant consultation with MAID providers and other medical or legal professionals? Is that a reasonable thing for us to do as legislators?

The question was for Ms. Guillemette first. If we have time, Dr. Gauthier, I would also like to have a comment from you.

• (1035)

[*Translation*]

**Mrs. Nancy Guillemette:** In fact, the third person who has been designated initiates the request for medical assistance in dying process, but the medical assessment is done by the team and the doctor. There actually have to be quite precise criteria to provide a framework for the expectations of the person with the illness regarding the point at which they want medical assistance in dying to be administered.

[*English*]

**Hon. Pamela Wallin:** Dr. Gauthier, do you think we can actually do that?

You've talked about the six stages and the defining, but we also know that these diseases are very individual. It may be hard to categorize people, which is of course the very essence of an advance request. I want to be able to make that request when I'm still thinking clearly and rationally, not after the fact or perhaps when I've morphed into a happy dementia state.

**Dr. Serge Gauthier:** The short answer is that we need to have clear descriptions of the stages that are common for most people as they go through a neurodegenerative condition such as Alzheimer's disease, and the wording has to be such that it can be understood by the average Canadian.

Could we perhaps have three choices, or something like that? It's something we can work on together.

**Hon. Pamela Wallin:** It's to have the patient's list of criteria—be it three, eight or 10—and have it match in advance with categories determined by the medical profession.

**Dr. Serge Gauthier:** It's something like that.

**Hon. Pamela Wallin:** Okay, thank you very much.

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

We'll now finish with Senator Martin for three minutes.

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

My colleagues have asked questions in the case of happy dementia. My mother suffered from dementia and recently passed away. I'm the eldest daughter. I feel like I'm just hearing my life described in all of the different possibilities. It's very individual. It's so complex.

You're right, Madame Guillemette. We need very good legal frameworks.

I know my mother's mother and her sister both suffered from dementia. I know that I'm at risk. This is a very important area of discussion for me.

I want to say that as policy-makers we need to find that fine balance between patient autonomy and managing the inherent risks that come with it. I want to ask the question of what we need to do to ensure that we find the right balance between autonomy and fully informed consent, given these inherent risks. I think many of you have touched on that in some of the responses.

Maybe I can start with Madame Guillemette first.

[*Translation*]

**Mrs. Nancy Guillemette:** In fact, I would say that it is a process that takes place over several years. The person who receives a diagnosis must not make a decision within the following two months. It is a process that takes place in collaboration with the doctor, the care team, the family, and the persons designated as mandataries. It is a serious process. I think it is possible to do it by putting guidelines in place and by the person having a safe environment around them.

I understand that it may affect you personally, given what you have experienced, but I am convinced that we can create a process that will respect people's values and their right to self-determination, while protecting vulnerable individuals. It is very important not to lose sight of that aspect.

[*English*]

**The Joint Chair (Hon. Yonah Martin):** Dr. Gauthier, would you comment?

**Dr. Serge Gauthier:** I think my colleague, Madame Guillemette, said it very well.

The dialogue we started today should be continued. We need more than three minutes and five minutes to talk about this, but we've had a good start.

Thank you for being there.

**The Joint Chair (Hon. Yonah Martin):** If there's time, Dr. Buchman, do you have any comments related to my question?

**Dr. Sandy Buchman:** I would just say, "ditto". I echo Ms. Guillemette's comments. I think it was said very well.

Most of the time as we approach decisions about the end of life, we do it in a collaborative fashion. I don't think an advance request is really any different. It's ultimately going to be one of our end-of-life options. We do it now with MAID. Ultimately, it's the person's decision for himself or herself. That's the autonomy and dignity that we're trying to protect.

The challenge I see is that sometimes individuals don't have that relationship with loved ones or other substitute decision-makers. That's a whole area of further discussion that we need to assess.

• (1040)

**The Joint Chair (Hon. Yonah Martin):** That's a very good point that you made. In fact, with language barriers as well, this is so complex. If the patient doesn't have the ability to fully communicate in ways that are effective, we'll have to make sure that there are supports for people with language barriers.

Thank you very much for your comments.

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

This concludes our second panel.

Thank you very much, Dr. Sandy Buchman.

[*Translation*]

With that, the meeting is adjourned.

Thank you as well, Dr. Gauthier and Ms. Guillemette.

I want to thank all the witnesses for appearing today before our committee on a very difficult and very complex subject and for providing answers to our questions. We are very grateful to them.

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