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# Special Joint Committee on Medical Assistance in Dying

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Joint Chairs:  
The Honourable Marc GarneauThe Honourable Yonah Martin





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• (1835)

[English]

**The Joint Chair (Hon. Yonah Martin (Senator, British Columbia, C)):** Good evening, colleagues, and thank you, everyone.

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

Before we begin, we have a vacancy in the vice-chair position, so the clerk will now preside over the election of a new vice-chair.

**The Joint Clerk of the Committee (Mr. Wassim Bouanani):** Pursuant to Standing Order 106(2), the first vice-chair must be a member of the official opposition.

I am now prepared to receive motions for the first vice-chair.

[Translation]

Mrs. Vien, you have the floor.

**Mrs. Dominique Vien (Bellechasse—Les Etchemins—Lévis, CPC):** I move that my colleague Mr. Michael Cooper be elected vice-chair.

[English]

**The Joint Clerk (Mr. Wassim Bouanani):** It has been moved by Madame Vien that Mr. Cooper be elected as first vice-chair of the committee.

Are there any further motions?

Is it the pleasure of the committee to adopt the motion?

(Motion agreed to)

**The Joint Chair (Hon. Yonah Martin):** Today we are continuing our examination of the statutory review of the provisions of the Criminal Code relating to medical assistance in dying and their application.

I'd like to remind members and witnesses to keep their microphones muted unless they are recognized by name by one of the joint chairs. Also, all comments should be addressed through the joint chairs. When speaking, please speak slowly and clearly. Interpretation in this video conference will work as in an in-person committee meeting. You have the choice at the bottom of your screen of floor, English or French.

With that, I'll welcome our witnesses for this evening's first panel.

Representing the Canadian Society of Palliative Care Physicians, we have Dr. Romaine Gallagher, clinical professor of palliative medicine, University of British Columbia, via video conference. From the Canadian Cancer Society, we have Kelly Masotti, vice-president of advocacy, via video conference, and Daniel Nowoselski, advocacy manager, hospice palliative care, also by video conference. Lastly, on behalf of The Dorothy Ley Hospice, we have Donna Cansfield, chair of the board of directors, by video conference, and Dipti Purbhoo, executive director, also by video conference.

Thank you all for joining us this evening and taking the time to help us in this important study. We're very tight for time this evening, so we will be quite strict with our timing. We'll try to give you a one-minute warning. Please keep your remarks to five minutes.

We'll begin with Dr. Gallagher, followed by Ms. Masotti and Ms. Purbhoo.

Dr. Gallagher, you have five minutes.

**Dr. Romaine Gallagher (Clinical Professor, Palliative Medicine, University of British Columbia, Canadian Society of Palliative Care Physicians):** Thank you, Madam Chair.

Thank you for allowing me to speak on behalf of the Canadian Society of Palliative Care Physicians. I'm here to clarify previous testimony about the state of palliative care in Canada.

There has been a struggle to define palliative care. The World Health Organization defines palliative care as follows:

[It is] an approach that improves the quality of life of patients...and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and...physical, psychosocial or spiritual [problems].

Addressing suffering involves taking care of issues beyond physical symptoms.... It offers a support system to help patients live as actively as possible until death.

Palliative care is explicitly recognized under the human right to health.

We should provide palliative care in response to needs, not according to prognosis and not just in the last weeks of life. Health Canada reports on MAID fail to indicate quality or quantity of palliative care received, but they show that palliative care is often provided late in the illness, with 21% receiving it in the last two weeks and 18% receiving it less than four weeks prior to MAID.

Research shows that late involvement in palliative care leads to suboptimal pain and symptom management, increased suffering, failure to discuss and adhere to advance care planning, and unplanned hospital deaths. An Ontario study of people dying of cancer who received palliative care for greater than six months before death, compared with those who had less, showed a lower chance of needing hospital care and dying in hospital and an increased chance of receiving care at home in the last month of life. CIHI data and other Canadian studies reveal that those who do not have cancer receive less palliative care and receive it later in their illness.

Palliative care needs national standards for provision across health care sectors to be embedded in accreditation processes that organizations must pass to receive health care funding. We must develop indicators that are proxy measures with respect to quality of life and not just place of death and when palliative care was accessed. We also need patient-related outcomes whereby we track symptoms and distress during serious illness. This will take some dedicated funding for several years to achieve, but then we would have accurate data to assess our care of those who have life-limiting illnesses.

Some state that most people seeking MAID do so because of existential suffering. This argument attempts to neutralize the potential influence of palliative care in mitigating suffering, and it reassures lawmakers that MAID is the only option for existential suffering and that there's no need to improve palliative care provisions, yet Health Canada reports existential suffering at 3%. It appears that MAID proponents characterize the loss of ability to engage in meaningful activities—listed as 86% of MAID patients—as existential suffering. If this all seems confusing, that is because it is nearly impossible to separate one kind of suffering from another. We cannot dump a bag of suffering into the top of something like a coin-sorting machine and have it sorted out into different denominations such as physical, psychological, social and existential.

It is important that you understand that the division between these different sources of suffering is artificial since all these fears are connected. For example, think of a person living with inadequately managed pain who has limited her mobility, heightened her dependency on her partner, causing her to feel like a burden, and undermined her sense of agency and sense of self. This is typical of the nature of existential distress seen in patients with life-limiting conditions. Controlling her pain gives her back her mobility and independence, and other practical and emotional support returns her sense of agency and reduces the feeling of being a burden. In other words, providing quality palliative care is very effective in alleviating existential distress, as are some psychological interventions specifically designed for patients with persistent suffering. There are decades of research and clinical practice behind this.

- (1840)

Palliative care is optimally delivered in teams because it takes a team to meet all the needs of a patient and their family. Team-based care has strong evidence showing improvement in symptoms and quality of life, less caregiver distress, reduction in ICU and hospital stays and reduced health care costs.

Canadians will suffer with life-limiting illnesses whether they access MAID or die naturally. They are counting on you to ensure quality, timely palliative care for all Canadians.

Thank you.

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

Next we'll have Ms. Masotti for five minutes.

**Ms. Kelly Masotti (Vice-President, Advocacy, Canadian Cancer Society):** Good evening.

Thank you, Chair and committee members, for having us here today. My name is Kelly Masotti and I'm the vice-president of advocacy, and with me today is Daniel Nowoselski, advocacy manager, hospice palliative care.

Before I begin my remarks, I would like to acknowledge that I am speaking to you today from the traditional unceded territory of the Anishinabe Algonquin people.

The Canadian Cancer Society is committed to supporting people with cancer and their caregivers by ensuring they have the information they need to make decisions about palliative care, advance care planning and end-of-life care, including medical assistance in dying. Since 2020, our helpline has responded to more than 300 inquiries specifically about palliative care, more than 200 about grief and bereavement and 40 related to medical assistance in dying.

Everyone with a life-limiting illness deserves care that provides comfort, dignity and choice. Palliative care isn't just for those in the last days or weeks of life. It doesn't mean death will come faster or that anyone has given up. In fact, research shows palliative care can help people live longer by focusing on care that helps maintain quality of life, relieve symptoms and provide support in the setting of their choice. For some, palliative care lets them step out of the role of caregiver and allows them to simply be a daughter, husband, sister or loved one. For others, it can be comforting to know their loved one is getting care to help reduce pain and minimize symptoms. For many, palliative care helps guide patients and their loved ones through the stages of life and grief that accompany it.

Critically ill patients are falling through the cracks when it comes to palliative care. According to CIHI, while people with cancer generally have greater access to palliative care than those with other chronic or life-limiting illnesses, the data says we still need to get better. Among patients who died in hospital with a cancer diagnosis, only 41% were hospitalized primarily for palliative care, and three in four had no indication of palliative care needs prior to their final hospitalization.

Access to palliative care differs by geography and population. Even when palliative care services are available, not all Canadians know about these services or how to access them. Those who are informed about palliative care often find out about it too late. Finally, those who access palliative care tend not to receive it in the setting of their choice.

At the same time, at the end of life many decisions need to be made, taking into account an individual and their loved one's values and preferences. According to Statistics Canada, while cancer is responsible for the death of more than one in four Canadians, it represents 67.5% of the underlying medical conditions of all reported MAID requests.

CCS respects and supports all Canadians with cancer by helping them make informed choices and autonomous decisions about their care. These choices include MAID.

I will now turn to Daniel.

• (1845)

**Mr. Daniel Nowoselski (Advocacy Manager, Hospice Palliative Care, Canadian Cancer Society):** Thank you, Kelly.

I'm speaking to you from the traditional and unceded territory of the Kanien'kéha, or Mohawk, in a place that has long served as a site of meeting and exchange among many nations.

Palliative care not only benefits the people who receive it and their loved ones. At a time when we are facing significant challenges in our health care systems across the country, CCS believes that investing in palliative care would also help relieve the pressures faced in other parts of our system and improve overall performance. However, the current specialized palliative care workforce is not large enough, and we do not have sufficient beds in hospices and communities to meet the growing demand and changing needs.

We recommend that the federal, provincial and territorial governments continue to prioritize palliative care in their bilateral funding agreements on health care to expand access to palliative care services and hospice beds. This includes increasing the availability of specialist resources for consultative advice, as well as education, orientation and training for all care providers in providing a palliative approach to care.

Furthermore, we echo the recommendations made by the Quality End-of-Life Care Coalition of Canada in their pre-budget submission regarding investments in research on palliative care and investing in data and standards for palliative care. Regarding access to MAID, a written submission from May outlined several recommendations regarding consistent access, data collection, ongoing program evaluation, and education and training for health care providers.

Ultimately, anyone with a life-limiting illness would benefit from greater and earlier access to palliative care from the point of diagnosis up to their death, but our health care systems do not have the capacity to consistently accommodate the choices someone with cancer and their loved ones would like to make regarding their goals of care, their setting of care or what their final days might look like. Everyone in Canada should have access to affordable, culturally safe and high-quality palliative care, as well as the ability to make autonomous decisions about the care that will impact the quality and outcome of their life.

Thank you.

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

Ms. Purbhoo, I understand that you have just joined our meeting. Thank you for joining us. You will have five minutes.

Will you please turn your camera on so we can see you on the screen?

**Ms. Dipti Purbhoo (Executive Director, The Dorothy Ley Hospice):** Good evening. I'm so sorry. I'm trying to turn my camera on, but we've been having some technical difficulties here.

I don't think my camera is going to turn on. Is it okay if I continue my talk without the camera?

**The Joint Chair (Hon. Yonah Martin):** I see nodding heads, so yes, Ms. Purbhoo. You have five minutes.

**Ms. Dipti Purbhoo:** Okay.

I have Donna Cansfield here, who is the chair of the board of directors at The Dorothy Ley Hospice. I'm going to ask her to start.

**Ms. Donna Cansfield (Chair of the Board of Directors, The Dorothy Ley Hospice):** Thank you. I apologize as well for our technical difficulties.

Good evening, and thank you for the opportunity to speak with you. This is very important to us. My name is Donna Cansfield and I am chair of The Dorothy Ley Hospice board of directors. I have served as both a volunteer caregiver and a member of the board in my over 30 years of involvement with the hospice.

I support an individual's choice at the end of life, but choice involves options. One option is the support of end-of-life palliative care that's provided not only in the community but also at a residential hospice. Palliative care must be available to all members of our diverse community, recognizing and respecting cultural differences, language restrictions and limited family support. Supporting an individual and their families is what we do.

Through care provided in the home with palliative physicians or at a hospice residence, respite support for caregivers provided by trained volunteers, day programs, ambulatory service care at a hospice and bereavement support for families, we navigate the complex health system for families that are frustrated with systems that rarely speaks to one another. We keep clients out of emergency departments and out of hospital beds.

This is done through kindness, caring and our amazing staff. This is what we do. It's an extremely less expensive option, and it has been our experience that it's an option often chosen instead of MAID. However, we still support the decision of the individual, and we also provide support if asked to do so.

If you want to help us and you believe in hospice palliative care, we could use your support, which would help others.

● (1850)

**Ms. Dipti Purbhoo:** I would like to continue. Thank you again for the opportunity.

My name is Dipti Purbhoo and I'm the executive director of The Dorothy Ley Hospice. I'm a nurse by background with over 25 years of experience in palliative and community care.

Palliative care is an approach to care that focuses on what matters most to the individual. Through pain and symptom management, education and support, the goal is to give the person as much time living with as much quality as possible.

Palliative care also focuses on helping loved ones through the process with information and support. It is provided by a team of people, including doctors, nurses, social workers, volunteers, family and friends. It is a powerful expression of compassion, kindness and caring, and it is something that each and every person and their family should have at the end of life. It is what we would all want for ourselves and our loved ones.

In Canada today, palliative care is not available to everyone. Access to palliative care is dependent on where you live, whether there are hospice palliative care services available, how much information you have about palliative care, whether you speak the language and whether your doctor or health care provider thinks it will help you. As a result, many people do not get access to palliative care, which often results in death in hospital without support, and in some cases people choosing medical assistance in dying.

Medical assistance in dying is a choice that is available to those with a life-limiting illness. However, when people choose MAID because they do not have access to all palliative care options to help ease their suffering, MAID is no longer about choice but is about having no choice and having no alternative but suffering with no help. MAID should not be a substitute for all the options palliative care can provide. It is but one option, not the only option.

In our experience here at The Dorothy Ley Hospice, we work with many, many patients at the end of life, as well as with their families.

**The Joint Chair (Hon. Yonah Martin):** You have one minute remaining.

**Ms. Dipti Purbhoo:** What we have heard is that people choose MAID because they don't want to be a burden to their family. They

don't want to suffer and die alone. They don't want to die in a hospital. They're worried about getting care at home, or they want control over how they die.

We have had many individuals here. We have an individual right now who has lived longer than the two months she was given, and she wanted medical assistance in dying because she didn't want to be a burden to her family. With the support of our team, she's still thriving and hopes to come to the hospice to die when her time comes. We had another client, in her late fifties, who recently had MAID in her lovely garden after a family celebration because she did not want her children to see her die.

In closing, the right to medical assistance in dying is very important to allow for choice. Even more important is access to palliative care as a human right for everyone so that everyone can experience end of life free of pain and can have as much time as possible to spend with their loved ones. Access to palliative care also ensures that those who do choose MAID are doing so because it is what they want, not because it is their only option to help with their pain and suffering.

Thank you for your time today. We apologize for our technical difficulties and for your not seeing us in person.

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

We're going into our first round of questions by MPs. We'll begin with Mr. Cooper for five minutes.

**Mr. Michael Cooper:** Thank you, Madam Chair.

I will direct my questions to Dr. Gallagher.

Dr. Gallagher, at a recent meeting of this committee, Dr. James Downar stated in his testimony that 98% of people who access MAID had received or had access to palliative care. By contrast, the data from the third annual Health Canada MAID report indicates that only 82% of those who had MAID received palliative care and only 88% had access. Those numbers differ from those presented by Dr. Downar.

As a representative of the Canadian Society of Palliative Care Physicians, can you shed any light on what the numbers are?

● (1855)

**Dr. Romyne Gallagher:** Yes, and I have several things to say about that.

First of all, there are no measures for the quality of palliative care. This is extremely important because people have trouble defining it, so actually measuring the quality is also an issue.

What we do know is that 20% had access to palliative care after they requested MAID. When you think about it, this means that someone can be suffering pain, loss of independence and loss of meaning for two years in the community, and if they finally request MAID and are admitted to a palliative care unit, they will be listed as having received palliative care. It's important to keep that in mind.

If you look at the people who did not receive palliative care, it is approximately 12%. However, it's said that palliative care was accessible 88% of the time. Was it refused because the MD was not aware, or was it refused because the MD did not understand palliative care and the fact that it could be provided? For instance, I've had people with MS who appropriately needed symptom management and were told that they were not able to have palliative care.

If you take the people to whom palliative care was not accessible—the 12% of the 1,474 people who didn't have access to MAID—that's 177 people who had no access. If advocates for MAID came to the government with evidence of 177 people not having access to MAID, I'm sure the media would pick it up and something would be done, but we are not seeing this kind of response to the palliative care needs of people.

I want to draw that to your attention. It is not a minuscule number of people who lack palliative care.

**Mr. Michael Cooper:** Are you citing Health Canada numbers?

**Dr. Romaine Gallagher:** Yes, I am.

**Mr. Michael Cooper:** We did have specific testimony saying 98% of those who do undergo MAID receive or have access to palliative care. Is that accurate?

**Dr. Romaine Gallagher:** I actually listened to that talk by Dr. Downar, and I was confused as to whether he said 98% or 88% of those who did not have palliative care had access to it.

I think there are huge problems with the federal public reporting because it's done by people who fill out a yes-or-no short-order form and often don't have extreme knowledge of palliative care. This data is at best deeply flawed, and at worst it's meaningless. We are told it's a critical component for supporting transparency and fostering public trust in the application of the law, but I do not feel it meets that goal.

**Mr. Michael Cooper:** Do you have any further data respecting access to palliative care beyond Health Canada data, or are you strictly relying on that?

**Dr. Romaine Gallagher:** No, there is actually an increasing number of studies on access to palliative care. As some of my colleagues have said in this hour, it depends on your postal code. It depends on your own knowledge—

**Mr. Michael Cooper:** I think my time is just about to expire, so Dr. Gallagher, could you provide the committee with any additional data that could shed light on the issue of access?

• (1900)

**Dr. Romaine Gallagher:** Yes, I certainly could. There are a number of studies I can send.

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

Next we'll have Mr. Maloney.

You have five minutes.

**Mr. James Maloney (Etobicoke—Lakeshore, Lib.):** Thank you, Madam Chair.

Thank you to all of the witnesses for being here today. Your presentations have been very helpful.

I'm going to start by addressing my questions to The Dorothy Ley Hospice. For full disclosure to fellow committee members, The Dorothy Ley Hospice is located in Toronto, in Etobicoke, in my community, so I'm very familiar with the good work they do and I want thank them for that. Because of that, I had occasion to participate in a Zoom call hosted by Dorothy Ley a few months ago—I believe it was in July—during which they invited people to come out and outlined the process involved in MAID with some statistics.

Many things struck me that evening, but one landed the most. The doctor who was doing the presentation suggested that when MAID was first legalized, none of the doctors—I believe it was 12—at Dorothy Ley wanted to be involved in the MAID process. Now that number has changed and the number is, I think, six or more. If I am correct on that, I would like to hear your explanation of why that is.

**Ms. Dipti Purbhoo:** Thank you so much, Mr. Maloney, for highlighting that.

Since 2016, we've seen a substantial change. We've just completed a review of not only our palliative care physicians but all of our staff in terms of their perceptions and thoughts about MAID. About 70% of our physicians have changed their perspective, and the reason for that, as they've stated, is that MAID has become more commonplace and people are more accepting of it.

They've seen that MAID can be one of the options in their tool kit as it relates to palliative care. When all other options for comfort, symptom management and relieving distress and suffering fail and the individual is still suffering and still asking for other solutions, they would never offer MAID, but if the individual brings up MAID, they have those conversations with them and exhaust that option for them. I think they have changed and evolved to consider MAID as one option in the tool box of options that exist for palliative care versus seeing MAID as something separate and distinct from palliative care.

**Mr. James Maloney:** There's been some evidence before this committee that it's an either/or situation—it's MAID or palliative care. If I understand you correctly, the doctors at your facility have come to the conclusion that it's part of the process; it's not an alternative.

**Ms. Dipti Purbhoo:** Absolutely. It's just one option; it's not a substitute for all the other palliative care options that exist.

In our experience working with individuals who are thinking about or requesting MAID, it is an informed choice and informed decision they're making. What our palliative care team does is talk to the individuals and families about what their choices are, why they are making this choice, what's driving it, what their fear is and what their concern is. They talk to them about all the options that might exist to address them. Then at the end of the day, if MAID is still something they wish to choose, they will support them in that.

In the process, MAID is one aspect of palliative care, but it has to be an informed choice and individuals need to understand that there are other options available to them. If after all that they still wish to proceed with MAID, then I think that's something we would support.

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

**Mr. James Maloney:** Okay.

Palliative care is funded through the province. All of us here agree that there's a severe lack of palliative care. Because MAID is available, should it be restricted in some way or limited because of the lack of provincial funding?

I'll put that out to all the witnesses.

• (1905)

**The Joint Chair (Hon. Yonah Martin):** You have time for one person.

**Dr. Romaine Gallagher:** I'll take it on.

**The Joint Chair (Hon. Yonah Martin):** Okay. Go ahead, Dr. Gallagher.

**Dr. Romaine Gallagher:** I'd like to make the point—and I think my colleague from Dorothy Ley also made it—that a person who has to choose between MAID and no funding doesn't have a choice. We've had several episodes like that in B.C. People could not get access to round-the-clock care, so they could not stay in their community and were offered either a transfer out of their community or MAID.

**Mr. James Maloney:** I'm sorry, but my question really was this: Should MAID not be available because of lack of provincial funding—

**The Joint Chair (Hon. Yonah Martin):** I'm sorry, but we're out of time. Thank you.

Next we'll go to Monsieur Thériault for five minutes.

[*Translation*]

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

Dr. Gallagher, do you provide palliative sedation?

[*English*]

**Dr. Romaine Gallagher:** Do I use palliative sedation?

[*Translation*]

**Mr. Luc Thériault:** Yes.

[*English*]

**Dr. Romaine Gallagher:** Yes, I do.

[*Translation*]

**Mr. Luc Thériault:** Do you provide medical assistance in dying?

[*English*]

**Dr. Romaine Gallagher:** No, I do not. I should tell you that I've been retired clinically since 2019, but when I was practising I did not provide MAID.

[*Translation*]

**Mr. Luc Thériault:** Thank you.

In your opinion, how is it morally more acceptable to provide palliative sedation than medical assistance in dying?

[*English*]

**Dr. Romaine Gallagher:** I'm not making a statement about morality. I provided palliative sedation very rarely, mostly for people with delirium at the end of life, because it is very difficult to keep a person comfortable and in their bed and calm if they do not have some degree of sedation. The use of sedation is not to end the life of the person; it is to make them more calm and make their symptoms more controllable. They are not the same.

[*Translation*]

**Mr. Luc Thériault:** Was it the patient himself who consented to this type of care?

[*English*]

**Dr. Romaine Gallagher:** Oh yes. It is—

[*Translation*]

**Mr. Luc Thériault:** So the palliative care you provided did not successfully relieve the existential suffering and anguish or the anxiety of the dying patient at the end of his life?

You offered him palliative care, but did you also offer him medical assistance in dying?

[*English*]

**Dr. Romaine Gallagher:** I'm not clear on your question. Are you asking me if I offered palliative sedation for existential suffering?

[*Translation*]

**Mr. Luc Thériault:** You told us about a patient in a state of anguish and anxiety who was delirious and in pain. Palliative care did not successfully relieve his pain and suffering, because palliative care can't relieve all types of pain and suffering. I imagine you agree with that.

When you offered him palliative sedation, did you also offer him medical assistance in dying?

[*English*]

**Dr. Romaine Gallagher:** First, I would say that delirium is a syndrome where a person is hallucinating and is often very confused and trying to climb out of bed and is maybe quite agitated. That is different from someone who has anxiety and existential distress, so what I'm—



[*Translation*]

**Mr. Luc Thériault:** How do you go about obtaining free and informed consent when the patient is in such bad shape?

Why do you consider that more acceptable than, say, an approach where one morning, as they are being accompanied on their journey toward death, a dying patient says they are ready to let go and decides to go ahead with medical assistance in dying?

How was what you were offering more morally acceptable than the alternative scenario, the one you didn't offer your patients?

• (1910)

[*English*]

**The Joint Chair (Hon. Yonah Martin):** You have about 45 seconds.

**Dr. Romaine Gallagher:** I'm not saying it's morally acceptable. I certainly work very hard to deal with someone's existential concerns. You may recall that in my talk I mentioned how interconnected all these fears are and how palliative care has a lot to offer for people who are suffering and who have—

[*Translation*]

**Mr. Luc Thériault:** I understood what you said, but I'm asking you that question.

Conscientious objection and moral objection to medical assistance in dying happen all the time. So I wanted to hear your answer to that question.

[*English*]

**The Joint Chair (Hon. Yonah Martin):** Thank you. That's your time.

I'm going to move to Mr. MacGregor for five minutes.

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

I would like to echo my colleagues and thank all of our witnesses for helping guide our committee through this study.

Dr. Gallagher, I would like to start with you. I take it from your comments that a patient-centric approach is very important to you in trying to understand what patients want.

We have had a number of witnesses here in previous meetings. I had Dr. Valorie Masuda from my own riding. She's a palliative care physician. We had a representative from TheraPsil who specializes in psilocybin and psilocybin therapy. We also had comments from Dr. José Pereira, who indicated a willingness to explore further research in this area.

You mentioned existential distress. There has been some promising research, notably from Johns Hopkins University, on how carefully administered doses of psilocybin, with the care and attention of someone who has expertise in this kind of therapy, have really allowed patients, particularly during end-of-life care, to gain a measure of acceptance in meeting their end.

I would like to hear from you with regard to your understanding of the state of research into that. Do you think our committee can

make some recommendations to try to make sure that type of therapy is more widely available to patients in palliative care?

**Dr. Romaine Gallagher:** Yes. I definitely think there's a lot more work to be done on dealing with existential suffering. I think we're relatively early into a detailed understanding about existential research and how to offer therapeutic ways to mitigate this. I think there's good promise for this, and I would certainly support that.

I actually took a little part in the training of Dr. Masuda, and I know she is a great resource to her community.

I think we should explore this. However, I don't want you to go ahead and do that without mentioning all the other things that I mentioned about being able to measure the kind of quality of care we're giving to people and enacting standards, because that's the way we raise the bar across the country.

**Mr. Alistair MacGregor:** Yes, and taking that in stride, but is recommending further federal funding and research into this area something you would support?

**Dr. Romaine Gallagher:** Yes, absolutely.

**Mr. Alistair MacGregor:** Okay, perfect.

I will turn to the Canadian Cancer Society on the same theme. I know a lot of cancer patients end up in palliative care and some choose to access medical assistance in dying, as is their right.

On the same theme of what seems to be promising research into the use of psilocybin and psilocybin-assisted therapy, does the Canadian Cancer Society have any comments on that and on what recommendations our committee might be able to make in this specific area?

**Mr. Daniel Nowoselski:** We are certainly exploring that. One of our research projects is associated with it, so we're going to try to get more information back to you on that.

We have certainly called for more access to funding for palliative care research specifically in this area. The Quality End-of-Life Care Coalition has an ask particularly around seed funding for research. This is a very difficult area in which to raise matching funds for research.

We will make sure to send that submission to you so you can understand more context around that and around the challenges of accessing funding for research on palliative care.

• (1915)

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

When it comes to palliative care, I don't know if we've spent a lot of time speaking about caregivers and the emotional and financial strain they can go through.

I will turn this to Dr. Gallagher. Do you have any comments about the supports that are currently available to caregivers and anything you would like to see us recommend in that area?

**Dr. Romaine Gallagher:** That's a great question. I would say, first of all, that people who are connected early to palliative care show a reduction in caregiver distress and show benefits even after a person has died. I also think, though, that we need some sort of financial benefits and help for caregivers because many patients and caregivers report out-of-pocket expenses when they have an illness. You never think about them until you actually have an illness and have to go back and forth to the hospital all the time.

I also think we could look at other things that aren't tax credits, because there are people who are poor enough that they never pay tax, and they don't benefit unless there are refundable tax credits. There are many more things we should do, because we cannot manage our health care system without caregivers. I would hate to think what it would be like without them.

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

I'll now it over to my co-chair for questions from the senators.

[*Translation*]

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

We will now go to the senators' questions.

Senator Mégie, you have the floor for three minutes.

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

My first question is for Dr. Gallagher or anyone else who would like to comment.

Some witnesses who appeared before us have said that there is very little access to palliative care across the country. One individual from Quebec told us that access largely depended on the patient's postal code.

What can the federal government do to help address the disparity in access to this type of care?

[*English*]

**Dr. Romaine Gallagher:** I think it would make an enormous difference if high-speed Internet and telehealth were accessible to all people. For instance, when I went to Haida Gwaii, I found out how poor the cell service there was. The nurses, in order to make a call, had to go to the beach to get cell service. They couldn't access any of the apps on their phones unless they were downloadable. That meant no house calls to a person at home. We have the technology to give palliative care much better accessibility, but I'm afraid it's going to cost money. I think there would be enormous benefits along with that.

The other thing is standards. I can't say enough about standards for palliative care. We are establishing the quality we expect every person to receive.

[*Translation*]

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

The next question is for the Dorothy Ley Hospice team.

When I worked in the medical field, I opened the Maison de soins palliatifs de Laval, whose mission was similar to that of the Dorothy Ley Hospice.

Is your organization funded by federal or provincial funds?

[*English*]

**Ms. Dipti Purbhoo:** In terms of our funding, 60% of our funding is from the provincial government and 40% must be fundraised, so that's about \$1.5 million a year. That's a significant strain on us, and it's growing every year because operating costs are growing. When you talk about accessible, high-quality care, funding for hospices is certainly an issue that needs to be addressed.

In terms of caregivers—

• (1920)

**The Joint Chair (Hon. Yonah Martin):** Sorry for the interruption, but we're not getting the French interpretation.

If you can speak slower in your response, that will help with interpretation. Thank you.

Go ahead.

**Ms. Dipti Purbhoo:** I indicated that 60% of our funding comes from the provincial government and 40% of our funding must be fundraised, so that's about \$1.5 million and it's growing every year. When we talk about accessible, high-quality care, we need to look at funding for hospices.

In terms of caregivers, the other things that are really essential for caregivers are information, support, advice, guidance and counselling along the entire journey. That is what we do at the hospice. We have exceptional staff who do that work, and I can't tell you how much distress it relieves for caregivers and for the individual. It also helps keep people home.

Some of those social supportive services, with the volunteers who go into the home, are also exceptional—

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

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

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

Thank you to all the witnesses. I really appreciate you reminding us that we have huge challenges in improving equitable access to high-quality medical care across Canada, and this absolutely includes palliative care.

I have two questions for The Dorothy Ley Hospice group [*Technical difficulty—Editor*] and then the second one.

I understand that the hospice provides high-quality palliative care, but you still see patients who request MAID even though they have received high-quality palliative care. For these patients, do they state that their request for MAID is due to not receiving quality palliative care, or do they choose MAID, even after they receive high-quality palliative care, for another reason?

**Ms. Dipti Purbhoo:** Individuals who request MAID in our care at The Dorothy Ley Hospice have received high-quality palliative care. However, as I said earlier, they are choosing MAID for a reason, whether it's because they don't want their family to watch them die and suffer in that way or because it's a choice for them or because their suffering still isn't relieved with all of the other options in palliative care.

Again, high-quality palliative care often prolongs life and often provides good quality of life. It doesn't mean that nobody will access medical assistance in dying, but it does mean that people will be making an informed choice on whether medical assistance in dying is really what they want in order to address their worries, concerns, distress or pain. There are other palliative care options that might assist them.

**Hon. Stanley Kutcher:** Thank you for that. I wholeheartedly agree with what you said.

We've heard concerns that people are receiving MAID because the quality of palliative care they get is poor. Would you know of any data showing that the people who have received palliative care and then chosen MAID have done so primarily because the palliative care they have is [*Technical difficulty—Editor*].

**Ms. Dipti Purbhoo:** I don't have data, but I do have anecdotal data. From understanding the high-quality palliative care that our organization delivers, I can certainly say that they are making the choice because it is something they want.

I would say, though, in my experience as a nurse in palliative care for many years, I have seen over the last many years people choosing medical assistance in dying if they can't get enough home care to support a caregiver to keep their loved one home, or if they can't get into the hospice because there are not enough residential beds. As I have also seen, when they're not able to access palliative care at the level and standard that I think Dr. Gallagher talked about, they may decide to choose medical assistance in dying.

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

[*Translation*]

Senator Dalphond, you have the floor for three minutes.

[*English*]

**Hon. Pierre Dalphond (Senator, Quebec (De Lorimier), PSG):** Thank you, Mr. Chair, and thank you to the witnesses for their contributions to our work.

My questions are for the representatives of the Canadian Cancer Society.

You said, if I understood properly, that 67% of MAID requests are related to people suffering from cancer. Do you have data on how many of them were receiving palliative care?

• (1925)

**Mr. Daniel Nowoselski:** Unfortunately, we do not. Given the quality and availability of data on palliative care access specifically in relation to MAID, it is not disaggregated in that way.

**Hon. Pierre Dalphond:** Based on your experience, is there a spectrum of palliative care that starts first at home and then moves to a special place afterwards?

**Mr. Daniel Nowoselski:** In an ideal scenario, it would depend on the situation and the wishes of the person receiving care. People could choose to go to a hospice if that's available to them, receive it at home or receive it in a hospital or long-term care home. We think that in an ideal scenario, they should be able to choose where to receive care. Often it's their primary care provider or a specialist who identifies them and transfers them to a palliative care specialist, but that can occur in many different settings.

**Hon. Pierre Dalphond:** Are they asking to stay at home as much as possible, or do they prefer to be in a specialized centre where they feel there's more care and they feel reassured?

**Mr. Daniel Nowoselski:** In the polling we have done, more respondents tend to say they would prefer to die at home, but circumstances differ depending on each individual case. I would also say that hospices aren't often available, particularly outside of urban settings, so the choice to die at home might be made because of a lack of different options, not necessarily because that's what their preference is.

**Hon. Pierre Dalphond:** Would it be possible to provide us the results of that survey or that research?

**Mr. Daniel Nowoselski:** Absolutely.

**The Joint Chair (Hon. Yonah Martin):** Thank you very much. We'll now go to Senator Martin for three minutes.

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

Thank you to the witnesses once again for providing us with such important insights.

My question is for Dr. Gallagher. As a representative of the Canadian Society of Palliative Care Physicians, why do you think MAID should remain distinct from palliative care?

**Dr. Romaine Gallagher:** There are a number of reasons for that. For about the past 40 years or so, palliative care has been striving to show people that we do not hasten death and we do not shorten their life. The problem with combining it with MAID is that there is confusion. That's one of the reasons. That's actually supported by a 2021 study of public knowledge and attitudes concerning palliative care among Canadian people. They found that those who had a high perceived knowledge about palliative care were more likely to associate it with care provided as a last resort at the end of life. Despite 40 years of work, people were still associating palliative care with end of life, so combining MAID with palliative care would definitely cause that.

The other reason is that there are still people who have fears that palliative care somehow shortens life. I've certainly met people like that who have those fears, particularly with the so-called opioid crisis. Many people are fearful of using opioids, so we have to work hard with that, as we do not want it.

The other reason is that when MAID was first legalized, many health care providers, not understanding either palliative care or MAID, sort of thought palliative care would deal with this because it deals with all the end-of-life stuff. It was very chaotic, and our concern is that if we went back to that, for health care funders that would probably seem like the ideal thing because then everything would be kind of jammed together and you would have no extra funding. You would have two programs coexisting together, which would be cheaper. We do not feel as though that would provide quality care.

The other reason is that it's been our experience that in certain situations, providing MAID actually ends up consuming palliative care resources. As we've told you tonight, there are problems with accessing palliative care. We have the same human resource challenges—

• (1930)

**The Joint Chair (Hon. Yonah Martin):** Could you complete that quickly, Dr. Gallagher?

**Dr. Romaine Gallagher:** Yes. Thank you.

We have the same human resource challenges that emergency departments everywhere have. We would like to use our palliative care resources to provide palliative care to all Canadians, obviously including those who want MAID, but we want to be seen as being distinct from MAID.

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

That brings our first panel to a close. I'd like to thank you, Dr. Gallagher, Ms. Masotti, Mr. Nowoselski, Ms. Cansfield and Ms. Purbhoo, for your testimony this evening and for answering the questions from the committee on the subject of palliative care and the issue of medical assistance in dying. It was very important for us to hear from you. We very much appreciate that.

With that, we will suspend very briefly as we prepare for our next panel. Thank you.

• (1930)

(Pause)

• (1930)

**The Joint Chair (Hon. Yonah Martin):** We will continue, colleagues.

It is my understanding that there is agreement for this to be a truncated session because there is a vote in the House. We'll go until 8:20 p.m. It has been agreed that everyone's times will be shortened by one minute, for both MPs and senators. All of us will give up a minute of our time so we can truncate this second panel.

I want to welcome our witnesses for the second panel. Thank you so much for lending us your time and expertise.

We have, as individuals, Baroness Ilora Finlay, Baroness of Llandaff and professor, by video conference; Dr. Henderson, senior

medical director of integrated palliative care, Nova Scotia Health, here in person; and Dr. Madeline Li, psychiatrist and associate professor, by video conference. Thank you all for joining us.

We will begin with opening remarks by Baroness Finlay, followed by Dr. Henderson and then Dr. Li. You each have five minutes.

Baroness, go ahead.

**Baroness Finlay of Llandaff (Professor of Palliative Medicine, As an Individual):** Thank you for inviting me.

As legislators—and I'm a legislator—we must ensure that legislation's protective role for the vulnerable is reinforced, not weakened, and that the state's duty of care is fulfilled equitably, as exercised via its clinical workforce.

Canada's physician-assisted suicide and euthanasia deaths show a disproportionately rapid increase, even compared to Benelux countries. Removing the foreseeable death requirement in effect creates death on demand. Evaluation of patients is purely subjective, and consultations have never been qualitatively evaluated. Doctors have an inherent power differential in a consultation. Offering lethal drugs as a therapeutic option gives the subliminal message that what lies ahead is so awful that you would be better off dead. Subconsciously, this may reflect unconscious bias or ignorance, shortcuts in care or cost-saving motives.

The so-called safeguards are only broad, qualifying criteria, rather than verifiable safeguards. For example, foreseeable death was incredibly loose, as prognostication is notoriously inaccurate. According to the Royal College of General Practitioners, prognosticating beyond a few days has a scope of error that can extend into years.

Doctors, by their very compassion, often fail to detect coercion. U.K. data reveals that one in five elderly people is affected by abuse, particularly financial abuse, and neglect in their own home. Similar situations seem to exist in other countries in the developed world. Mental capacity impairments and distorted thinking are features of mental illness, with or without concomitant physical disease. Most clinicians are inadequately trained or experienced in assessing capacity.

Hence, including mental illness undermines suicide prevention policies and discriminates against those with mental distress by signalling they don't warrant ongoing psychiatric care or are of less value in society. The emerging accounts of those in poverty who are opting for MAID suggest an abandonment of society's duty to care for this group of citizens, yet many who strongly wish for death at one time later enjoy life and contribute to society in many unpredicted ways.

The drug mixtures used to end life have never been scientifically evaluated. Propofol's duration of action is short, at five to 10 minutes, as it's rapidly distributed in the body, yet rocuronium has a very long duration of total paralysis, making it likely that some patients will have regained consciousness as they die of asphyxia but appear to the observer to be tranquil, as they cannot move a muscle to signal distress.

Good palliative care does not include MAID. In my written submission, I gave three definitions of palliative care. All emphasize improvement in the quality of life for patients, their families and carers, aiming to help people live well until they die.

Distress and suffering require meticulous diagnosis through working with the patient, particularly where distress is amplified by financial worries, loneliness, fear and hopelessness. Any improvement can often be obtained very rapidly. I can give you an example of a man who referred to overwhelming distress, with his wife and daughter both in tears. His pain and nausea were controlled within an hour. All three commented they never believed things could be so greatly improved.

Medical assistance in dying is a euphemism for physician-assisted suicide and euthanasia of those thought to be terminally ill. It cannot be applied when the previous requirement of foreseeable death has been abandoned, because those being given lethal drugs are not dying.

In summary, Canada would do well to abandon the current expansion of its MAID law, which is an existential threat to those with disability or mental illness. Canada should invest in adequate specialist palliative care and move the provision of lethal drugs outside of health care, with prospective evaluation of the application consultations, research into the cocktail of drugs used and research into the short- and long-term effects on the bereaved.

• (1935)

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

Next we will have Dr. Henderson for five minutes.

**Dr. David Henderson (Senior Medical Director, Integrated Palliative Care, Nova Scotia Health, As an Individual):** Thank you.

My name is Dave Henderson and I'm from Nova Scotia. I've been asked to speak as a palliative care physician. I'm the former president of the Canadian Society of Palliative Care Physicians. That was a few years ago, when MAID was initially starting up in Canada. I'm also the former president of both the New Brunswick Hospice Palliative Care Association and the Nova Scotia Hospice Palliative Care Association, and former board member of the Canadian Hospice Palliative Care Association. I currently chair a group we call Palliative 4 Canadians. It's made up of the senior leadership from four different organizations in Canada, and its sole purpose is to try to improve palliative care for all Canadians. They are the Canadian Virtual Hospice, Pallium Canada, the Canadian Society of Palliative Care Physicians and the Canadian Hospice Palliative Care Association.

I'm not going to reiterate a lot of the great comments that have been made by many of my very esteemed colleagues. You have all

that information. I want to speak about some other issues that I feel are very important as we are looking into this issue.

I want to start off by saying that I'm not a religious man. I have said on several occasions in several different presentations I've done that I'm pretty sure I'm going straight to hell. I look forward to seeing many of you there as well. That's my standard, token maritime humour if anybody missed it.

**Voices:** Oh, oh!

**Dr. David Henderson:** Unfortunately, many palliative care physicians who make any kind of seemingly negative comments towards MAID are quickly looked at as being overly religious or having other reasons for being concerned. I want to make it clear that I actually refer patients to colleagues of mine who provide MAID. I'm not against it from that perspective, but I do see a lot of concerns, as do some of the colleagues I work with who actually provide the service. I think it's really important that we look at these.

My theme tonight is that it's time for a reality check.

First of all, to me, health care in Canada is in the most fragile state we've ever experienced due to the lack of planning for the exponentially aging demographics we are currently living with. Not only are many Canadians reaching the age at which most need more health care, especially in hospital, but the health care workforce is also among this aging demographic. As we're seeing with that, new health care professionals no longer have the comfort of having seasoned colleagues to mentor them as they start their careers.

Many are feeling moral distress and feeling overwhelmed, and they are subsequently leaving health care in general. I'm sure you have all heard of that. The numbers are quite staggering, even among young health professionals, who are getting out of health care altogether, which is a terrible shame. It's putting this country in such a delicate, desperate situation.

Subsequently, this is leaving our patients with less-experienced providers, who are having to take on workloads they aren't used to without having had the opportunity to gain the knowledge and skills to meet the needs. This creates difficulties for all patients but especially for those who are dying or those in vulnerable positions, as we've talked about, given our poverty issues and the many other issues we face in our country.

I'm very concerned that this has opened the door for medically assisted death to be, potentially, a path of least resistance. As we see people getting more and more overworked, tired and exhausted, unfortunately this could become an easier pathway. Things tend to take the path of least resistance. I'm also concerned that the government has given health care professionals essentially a licence to kill without having significant checks in place to ensure that people are assessed properly and thoroughly. That comment was made up just minutes ago.

Canadians agreed that people living with a terminal illness with foreseeable death should be given an opportunity to seek voluntary euthanasia, and the laws were amended. Many people spoke up at that time about the worry of the slippery slope and they were quickly dismissed. Here we are a very short time later with MAID being available to virtually any person for any reason, and I ask, is that what the Canadian public actually wants?

If the majority of society feels that autonomy trumps all, as seems to be becoming the way, and that every person can end their life at their choosing, then so be it. However, we are still responsible for protecting the vulnerable and ensuring that people have a choice that includes access to palliative care, mental health and social supports, pain specialists and a health care system that allows for dignity for all, not just those who want to end their life.

• (1940)

I want to make reference to testimony that has come previously, again, from colleagues such as Dr. Leonie Herx and the Canadian Society of Palliative Care Physicians, who have outlined some of their concerns and ideas for how to remediate some of them. I know you've heard from—

**The Joint Chair (Hon. Yonah Martin):** I'm sorry, Dr. Henderson. Will you wrap up at this time?

**Dr. David Henderson:** I'll finish at this point. Thank you.

**The Joint Chair (Hon. Yonah Martin):** Thank you. I'm sorry about that. I should have given you the one-minute warning, but I was listening to your speech.

Last we have Dr. Li.

You have the floor for five minutes.

**Dr. Madeline Li (Psychiatrist and Associate Professor, As an Individual):** I'd like to thank the joint chairs and committee members for the opportunity to participate in this study.

I am a psychiatrist at the Princess Margaret Cancer Centre, an associate professor at the University of Toronto and a scientist with a research focus on emotional distress and suicide in cancer, and this includes MAID research. I led the development of the MAID program for the University Health Network, served as an expert witness on the Lamb case and am currently the scientific lead for CAMAP's MAID curriculum development project. However, I am speaking today as an individual, so all opinions expressed are exclusively my own.

I am also a MAID assessor and provider, and what I'd like to tell you today is that I have significant concerns about the pace and process of the expanding MAID legislation.

I'd like to begin by recognizing that practitioners all have values that sit on a continuum of whether they prioritize patient autonomy or the protection of vulnerable persons. I personally lean more towards the duty to protect, largely reflecting my belief that MAID for those with a reasonably foreseeable natural death, or RFND, is literally assistance in dying, while MAID for those without an RFND is technically assisted suicide. This opinion underlies the four points I'd like to make.

My first point is that there has been insufficient attention given to the psychological dimensions of palliative care. Although psychological suffering has clearly been shown to be the primary driver of the desire for MAID, we have not adequately captured data on access to psychosocial care or emphasized the need for targeted research and funding in this area.

Second, as was just said, I've yet to see a public opinion poll on whether the Canadian populace is in favour of MAID for all forms of life suffering, and in particular for psychosocial or structural vulnerability. It's an important question, because I believe the Canadian populace—and maybe even legislators—are not aware of who has been qualifying for MAID. I suspect it may come as a surprise to learn that what are essentially “completed life” cases have been happening in Canada since even before Bill C-7, because no one reaches older age without some form of qualifying chronic illness like arthritis, COPD or diabetes, and psychosocial vulnerability often underlies these requests.

Conceptually, MAID and palliative care are arguably distinct, but I believe that clinically speaking there needs to be better integration to ensure high-quality end-of-life care, with attention to vulnerability. The thing is that everything about MAID except for the five minutes of the lethal injection is palliative care. All the initial conversations with a patient about whether to apply for MAID, optimal symptom management until they do, guidance about choosing when to go ahead with it once they're approved and support for the family after they've received it are really most safely done via palliative care. However, to engage the palliative care community, we need to demonstrate that we're practising MAID carefully, consistently and for palliation, but the legislation hobbles us in this. I've certainly had cases in which I felt compelled to provide MAID against my better clinical judgment because the law did not adequately protect. I'd be happy to describe such a case, if asked.

This leads to my third point: The current legislation leaves too much responsibility in the hands of clinicians, whose application of the eligibility criteria according to their own values can render the legislative safeguards impotent. As said earlier, this is because incurability can include treatment refusal; an advanced state of decline may not need to be progressive; suffering is determined only subjectively; and “reasonably foreseeable” is not legally defined at all. The absence of a definition of RFND is crucial in light of Bill C-7, as patients with prognoses of several years or those who refuse preventive care or who voluntarily stop eating and drinking can be placed on the supposedly palliative track one, in which there is no longer even the mandatory safeguard of a 10-day reflection period.

This brings me to my final point, which has also been made: Canada needs some standard mechanism of oversight to review cases. This has been proposed for mental illness as the sole underlying medical condition, but I believe it's required for many MAID cases or at least for all track two cases.

In sum, I'd like to see four things: increased attention on the psychological dimension of MAID, a determination of whether there is a public mandate for MAID for any form of suffering, a legal definition of RFND and some form of federal oversight. Under what circumstances a person should receive MAID cannot be left to the variable opinions of individual practitioners, because that is the responsibility of the government, which really should reflect the will of the Canadian people.

Thank you.

• (1945)

**The Joint Chair (Hon. Yonah Martin):** Thank you very much to all of our witnesses in the second panel.

We'll now go into the first round of questions. As agreed, it will be four minutes for each MP.

We'll go to Mr. Barrett for four minutes.

• (1950)

**Mr. Michael Barrett (Leeds—Grenville—Thousand Islands and Rideau Lakes, CPC):** Thank you, Madam Chair.

Baroness Finlay, my question is for you. You are a member of the British House of Lords who has studied euthanasia regimes and has a professional background as a physician and a professor with attention to palliative medicine. How, in your view, is Canada being perceived from abroad regarding our MAID policies and practices?

**Baroness Finlay of Llandaff:** I think if I could put it very simply, it is being viewed with great concern because of the rapid expansion and the stories coming out in the press of people who are opting for MAID because they can't pay their bills. They're frightened financially. That isn't a valid medical reason to have doctors end lives.

There's also concern about extension into mental health because of suicidal ideation, which can fluctuate. People can go on to live very full lives if they're taken through their crisis and supported. It is viewed, I think, with great concern.

**Mr. Michael Barrett:** This committee has recently heard testimony that Canada should consider expanding MAID to infants with a life-limiting prognosis in order to address the terrible suffering that those infants might undergo. I must note that I fundamentally disagree with this suggestion because I believe that it devalues persons with disabilities and that no child should have a question mark put over their life because society deems that life to be optional.

Can you tell us about the field of pediatric palliative medicine and whether MAID is the compassionate choice in those situations?

**Baroness Finlay of Llandaff:** I would say that it isn't a compassionate choice at all. It might be a convenience for people, and certainly the long-term care of a child with a lot of disabilities may be financially draining and emotionally draining on the family, but if you're going to focus on the child, you have to have evidence that

the child is suffering. You have to have evidence that the child wants something different from their current existence, and you have to be careful that you're not reflecting disability phobia within society and a discordant view of disability.

There is a real difficulty there: Where would you put the line anyway?

**Mr. Michael Barrett:** Thank you very much.

Dr. Henderson, how have palliative care resources been impacted by the implementation of MAID legislation in Nova Scotia and elsewhere in Canada?

**Dr. David Henderson:** Ultimately, we haven't seen a significant increase in human resources at all. I know that a colleague of mine talked about things being a lot better in one spot here in Ottawa, but that's very few and far between. We're struggling. We have wait times for patients for access to palliative care in Nova Scotia.

I mentioned the challenges now faced by the palliative care teams, partially because we are part of the aging demographic, so we're not even keeping up with those in the palliative care specialty teams who are retiring. We're not producing new specialists quickly enough. There aren't enough positions open for training in Canada, and that's something we've been talking about for quite a while with the universities to try to increase that.

Also, there's a lack of primary care. News on that just came out yesterday in Nova Scotia. Ultimately, we have a population of about a million people, so respectively it's not that large compared to other places in the country. However, about 120,000 people now don't have a primary care provider. That's like one in 10 people in our province.

As those people don't even have access to primary care, the only way they receive palliative care is that they end up in the emergency department and subsequently get referred. Our palliative care teams see these people and virtually have to hang on to them because there's nobody else to care for them. That's creating another load on our palliative care teams, and that's becoming more and more challenging.

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

We'll next go to Dr. Fry.

You have the floor for four minutes.

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

I am listening to two panels, the one an hour ago and this one, and I must say that some of the things I hear concern me. First and foremost, I buy and I accept the idea that we need to have palliative care accessible across the board. We know that provinces are responsible for that, so we need to look at some kind of universal accessibility, regardless of where you live in Canada, to good palliative care.

I hear that we don't have enough human resources to deliver palliative care, especially specialists. I'm hearing that and I buy all that. I accept all that, but what I am a little concerned with is, does anyone on this panel believe that palliative care and MAID are actually interchangeable, or that they're separate and you might have one or the other, and not that it's a continuum of care? If palliative care does not work, if a person's existential suffering becomes so great, then who are we to say that somebody is not suffering existentially?

How do we know that? Especially adults.... I accept the question that small children don't know and can't articulate, but for many adults, existential suffering is exactly what that is. We know that it sometimes can.... We heard it from one of the panellists in the last hour, who said that some people get great palliative care, yet they just don't want to continue because whatever they're feeling, whatever they're suffering, is just too much.

If, all things being likely, we have great palliative care, we get money put into it, it is universally accessible and we have enough human resources to train and deliver good palliative care, my question is this: Could a person who was undergoing all that, with the ability to get it without any problem about the ability to pay—as we know, in Canada medical care means you shouldn't have to worry about the ability to pay.... Do any of you believe that a person should be forced to stay in palliative care and not be offered MAID if they so choose?

I notice that Dr. Li is shaking her head, so perhaps, Dr. Li, I'll direct that question to you first.

• (1955)

**Dr. Madeline Li:** I absolutely take your point. I support the availability of MAID for end-of-life patients, and I certainly agree that I don't think the minority of patients who want MAID and go ahead with it are doing so because of a lack of access to palliative care.

I think the question was asked in the last panel about what proportion of patients who receive MAID have accessed palliative care. The last federal report tells us that: 82% of people who have received MAID have also been in receipt of palliative care. Also, the criticism of that was that it was clinician-reported. At UHN, my hospital, we have looked at actual receipt of palliative care services, and it's closer to 100% of our oncology population who accessed and received MAID and have also received good palliative care.

**Hon. Hedy Fry:** Thank you, Dr. Li.

How many more minutes do I have, Chair?

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

**Hon. Hedy Fry:** I'm probably going to make a statement and not ask a question.

I think we've had a lot of people asking what other people think about the Canadian system, what society thinks, etc. At the end of the day, the Supreme Court ruled that it has to be section 7 of the charter, with “the right to life, liberty, and security of the person”, and that means it doesn't really matter what other people think. People, and society in general, should not be judging whether you or whether one should choose palliative care. It's the clinician—

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

**Hon. Hedy Fry:** It's the clinician who should work with the patient to do this.

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

**Hon. Hedy Fry:** Thanks, Chair.

**The Joint Chair (Hon. Yonah Martin):** Next we'll have Mr. Thériault for four minutes.

[*Translation*]

**Mr. Luc Thériault:** Thank you.

Dr. Henderson, what we're hearing from you this evening is that we need to wake up. I fully agree with your call for better health care.

I'd like you to explain to me what you mean when you say “autonomy trumps all” in advocating for, say, medical assistance in dying as opposed to palliative care.

As far as I know, individual self-determination is enshrined in law, and in matters of health, no one can intervene with a patient without their free and informed consent. That's what autonomy and self-determination trump all means, even in emergency situations.

[*English*]

**Dr. David Henderson:** Thank you very much.

In my experience, the majority of people we see requesting MAID are often well educated. I haven't seen very many people who have a lot of physical symptoms, so existential distress certainly is something, but more and more I'm seeing people who want that personal autonomy to choose their time. They want to have a time when families can come and be present, and they look at it almost like planning a vacation versus planning their death. It sounds strange but it is strange when you experience some of that.

My concern is that there's a proportion of health care professionals in this country and a proportion of the population who are really looking at having autonomy in the sense that this needs to be available for absolutely everybody. I'm not saying it shouldn't be, but before we push it that far, we have to remember that there are people who don't live a life of autonomy. They've been struggling with financial difficulties; they're responsible to other people, or other people are caring for them, so already they don't get to make a lot of their own life choices. That doesn't mean they shouldn't have this choice, but do they perceive it as truly a choice? That's the challenge and the struggle there.

That's why I'm so concerned that we need to be extremely careful with this. I don't think we've had the proper checks and balances in place. I know we've heard various concerns across the country, and I never hear of any follow-up on those cases.



A colleague of mine gave an example. For any of us to prescribe an opioid, there are provincial bodies that now monitor our prescriptions, and if a patient of mine gets a prescription for an opioid from two other physicians, I get a letter saying that this patient has done this. We're trying to make sure that the person's not using opioids inappropriately. Does anybody get a letter about a patient who has had MAID or a physician who's done a large number of cases?

• (2000)

[*Translation*]

**Mr. Luc Thériault:** I'm sorry to interrupt you, Dr. Henderson, but I don't have much time left.

[*English*]

**The Joint Chair (Hon. Yonah Martin):** Yes, you have 30 seconds.

[*Translation*]

**Mr. Luc Thériault:** You'll agree with me that personal autonomy can't be reduced to economic or social autonomy.

When we talk about a person's dignity, we're referring to their ability to make a choice. Therefore, we must not take away their ability to choose between continuing with palliative care and getting support until death. People don't suddenly decide to request medical assistance in dying.

[*English*]

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

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

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

Dr. Henderson, I'd like to start with you. I had the opportunity to visit your beautiful province in September, and while I was there I had the opportunity to meet with some members of the legislative assembly of Nova Scotia to talk about the intersection between the federal government and the provincial government specifically on health care.

One of the things they mentioned to me was that the current funding formula is not working very well for Nova Scotia because your demographics tend to lean heavily towards the elderly end of the spectrum. Of course, the complex care needs and the palliative care needs are, per capita, a bit more of a burden for the Province of Nova Scotia to bear.

You have identified how health care in Canada is in crisis. In my province of British Columbia, particularly on Vancouver Island, we do have a fairly high population of retirees as well. With what I've heard from the MLAs, do you have anything to add, from your perspective of having practised, on how that federal-provincial partnership is going?

**Dr. David Henderson:** It certainly comes down to the dollars and cents of it. I've been involved in this at the national level enough to know—and we've tried as a group to bring together the provincial governments and the federal government because politics often gets in the way of doing the right thing. I'm not the right guy to say how money should be divvied up and such, but I think we need to have a really serious look at how we're delivering health care.

The issue of caregivers was brought up earlier. I think that for our health care system to survive the next few years, we're going to have to look at how we can compensate our caregivers, because we're not producing enough professionals and allied health people to be able to carry the load.

• (2005)

**Mr. Alistair MacGregor:** I appreciate it. Thank you.

I'm just going to take note of the time here.

In my final couple of minutes, Dr. Li, I would like to turn my next question to you.

In your opening remarks, you really made it a point of underlining the psychological suffering part of it. Certainly we've heard a number of other witnesses talk about the same.

We have also had witnesses here, and I've had a doctor from my own riding. We've had a representative from a company that is involved in psilocybin and psilocybin-assisted therapy because that is involved in trying to help patients in end-of-life care come to terms with that existential crisis, that psychological suffering.

Are you aware of some of the research that's been going on? Do you have any comments on that? Would you like to see the federal government invest in more research in this area as a possibility that it might assist patients with the quality of their care?

**Dr. Madeline Li:** Thank you for that question. I have lots of opinions around this.

Absolutely, I would like to see more funding for psychedelic research, for psychosocial research in general—and psychedelics are a part of that. I would be wrong to turn that down, because I am running a.... I've just submitted to CIHR for funding for a study on psilocybin in cancer and palliative care, so I certainly think that research needs to be done.

I want to give a caveat, which is that it's not going to be the panacea or antidote to MAID in any way. I finished a clinical trial looking at ketamine, another type of psychedelic, in palliative care, and I published a paper of a case series of three patients, and what—

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

**Dr. Madeline Li:** It doesn't necessarily change a patient's mind.

**The Joint Chair (Hon. Yonah Martin):** Thank you. Sorry, but I think we need to just quickly receive—

I see Gary's hand. It's probably related to the same matter.

**Mr. Gary Anandasangaree (Scarborough—Rouge Park, Lib.):** Yes. We see that the bells are ringing, Madam Chair. I'm wondering if we could all agree to continue the meeting for another 15 minutes to conclude with the senator's interventions.

**The Joint Chair (Hon. Yonah Martin):** Is there unanimous consent?

**Some hon. members:** Agreed.

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

I will now turn this over to my co-chair for questions from the senators.

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

We'll begin with Senator Mégie for three minutes.

[*Translation*]

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

My question is for Dr. Henderson.

Dr. Henderson, in an interview you gave, you said that many people fear palliative care. They believe that if they're admitted to palliative care, they will die faster.

What do you say to those individuals?

I'm going to quickly ask the next question so that you can answer me within two minutes.

In your opinion, what role can the federal government play in addressing the general public's lack of knowledge about palliative care?

[*English*]

**Dr. David Henderson:** That's a great point.

We actually said, when MAID was initially coming along, that there needed to be a national education campaign on palliative care, helping people understand what palliative care is, but then also what MAID is too, so that the public would be aware that this was actually available, which could help us reduce the risk of coercion. If the public knows that it's available, then they ask us. Right now we rely on them making a suggestion that there's something...or that life is intolerable, and then we will say, "You know that this is legal," and we discuss it further.

With palliative care, patients are still afraid to this day that we're going to get involved and that they're going to die sooner. We try to reassure people that we actually discharge people from our program all the time. People will come on our program. We'll help them address their physical symptoms, help them start working through some of their psychosocial issues, and help make sure they have addressed things such as advance care directives and things like that.

If they're doing really well, then we step back and they continue on with their primary care people, plus their oncologist or whomever. Then we're able to get involved again when necessary. Reaffirming that with patients and families helps to reassure them that we're not there for just the last days and hours of life.

• (2010)

[*Translation*]

**Hon. Marie-Françoise Mégie:** Thank you, Dr. Henderson.

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

We will now go to Senator Kutcher for three minutes.

[*English*]

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

Thank you to the witnesses.

I have two questions.

The first one is to both Dr. Henderson and Dr. Li. The second one is to Baroness Finlay. I'll ask them together, and then ask you to respond.

Dr. Henderson and Dr. Li, in your opinion, how could the federal government nudge provinces and territories to provide better quality palliative care to those who require it? That's the first question.

Baroness Finlay, has the National Health Service substantially improved palliative care in the U.K. over the last few years? Compared to Canada, what percentage of people in the U.K. have rapid access to quality palliative care?

Dr. Li and Dr. Henderson can go first, if you don't mind, please.

**Dr. Madeline Li:** I'm happy to answer that.

As I said in my statement, I think what has been missing in better quality palliative care is a focus on psychosocial care, because that's what underlies existential distress, which is what psychosocial care addresses. It's what underlies the request for MAID. I think there has not been enough attention, so there needs to be more investment in research and the delivery of end-of-life psychotherapies, such as CALM or dignity therapy or meaning-centred psychotherapy. They exist, but they're not disseminated, and additional research needs to be done on the dissemination.

**Dr. David Henderson:** I agree 100%. I think the federal government could pass down some words of recommendation to our professional colleges. I'll pick on the colleges for social work nationally as they tend not to do any specialized training at all. There's a great place and such a great need, and the social workers, in their training, could be learning more about things like dignity therapy. We tend to have to teach all the social workers a lot of this stuff when they come out before they start working in palliative care, because they don't get their core competencies in palliative care during their training programs.

Canada has done a really good job of looking at core competencies for social work, for primary-care physicians, for nurses, for almost everybody in the country. There's a national document that talks about that. Nova Scotia and British Columbia have produced their own provincial documents on competencies in palliative care for virtually all health care professionals. Those competencies need to be integrated within the professional schools so people have the skill sets to be able to deal with this.

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

Baroness, you have about 20 seconds for your comment.

**Baroness Finlay of Llandaff:** Very rapidly, you have to differentiate generalist palliative care provision from specialist palliative care provision. We have just changed the law so that specialist palliative care and palliative care are core parts of NHS provisions. One person not getting the care they need is one too many, I would have to say. Really, the difference is between access to specialists and those who get general care.

When the generalist can't cope, the person should be referred to specialist palliative care. Specialist palliative care cannot look after everybody who's dying, but everybody who is facing the end of their life needs good care. Those skills are then transferable to other aspects of medical care for people with distress, for whatever reason, including those bereaved because they've lost somebody suddenly, or whatever. Those are transferable skills, and they must have standards that they're measured against.

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

We'll go to Senator Dalphond.

[*Translation*]

Senator Dalphond, you have the floor for three minutes.

[*English*]

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

My question will be for you, Dr. Henderson. You're so close. I understand from the previous witnesses—and I think Dr. Li mentioned it—that 82% or even more of those receiving MAID had previously received good palliative care. Would you agree with this or not?

**Dr. David Henderson:** No, I actually don't. We don't know that for sure—well, the thing we do know is that 18% to 20% of the people from that study, first off, didn't receive any palliative care. There were another 20% who received palliative care only in the last 14 days of life, and that's not enough time, especially if you're dealing with psychosocial suffering. You don't fix or remedy that in 14 days.

• (2015)

**Hon. Pierre Dalphond:** Based on your experience—you're not a MAID provider, but a palliative care provider—have many of your patients, after a certain moment, asked for MAID?

**Dr. David Henderson:** Oh, yes, for sure.

**Hon. Pierre Dalphond:** Would you dismiss their request or agree to the request?

**Dr. David Henderson:** We actually teach also. We never abandon the patient.

There was a comment made about having to choose between MAID and palliative care. If the person's receiving palliative care, they can continue to receive palliative care right up to the time they have MAID. We don't intend it ever to have to stop unless the patient does not want to continue with palliative care. It's always available.

We teach, and we taught for years and years before this became available, that when someone says they think life's not worth living, we start by exploring that. We inquire, “What do you mean by that?”, so they can say, “I don't feel I want to live anymore.” Then we talk about what the root cause of that is. That's one thing that is lacking in a lot of the assessments for MAID when palliative care is not involved. The assessment involves only whether they qualified for MAID; it doesn't ask what the root cause of someone's suffering is and how we can fix that.

**Hon. Pierre Dalphond:** You say that because you did some MAID assessments?

**Dr. David Henderson:** No, it's because I work with people who have done MAID assessments. I was actually involved in developing the policy and developed a tool to help people who didn't work in palliative care to be able to do assessments, only to be told that doing those would take too long.

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

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

With that, the panel is coming to a close. I want to thank our witnesses this evening: Baroness Finlay, Dr. Henderson and Dr. Li.

Thank you for your forbearance with our slightly compressed schedule.

**The Joint Chair (Hon. Yonah Martin):** Do I have my three minutes?

**The Joint Chair (Hon. Yonah Martin):** I beg your pardon. That was my mistake. I forgot one of the senators, my own co-chair. I'm in trouble now.

**Voices:** Oh, oh!

**The Chair:** Please go ahead, Senator Martin. You have three minutes.

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

My first question is for Dr. Henderson. You mentioned earlier in a response that we haven't had the proper checks and balances in place, so I want to ask how we can improve oversight and monitoring of MAID to ensure that Canadians are not choosing it because they lack access to the necessary resources needed to live, including palliative care. What is needed?

**Dr. David Henderson:** Again, I'm not the expert on this. This is such an important thing, and it's such a definitive thing. Somebody's life ends with this. I mean, there's not much more importance than that, so we need to make sure that we're doing this right. It's legal now, and it's something that is being used. We just need to make sure we're doing it right.

I think there needs to be an oversight body—and perhaps not even within the government—that has the ability to review cases. There also need to be some national guidelines around what cases you review. If somebody doesn't follow the guidelines, what are, clearly, the consequences for not following those so that physicians don't get surprised at the end of the day when in good faith they provided MAID, only to find out they did something wrong, and they have no idea what the consequences are going to be? Those things all need to be very much cleared up and very transparent so that everybody knows the game and what the rules are.

To me, there should be audits. I think you could flag high producers, basically. People who are doing a lot of cases probably should have more of their cases audited to make sure everything went well and was above board. Then there should be just random checks on other people providing the care. That's what happens already in health care for family physicians and all physicians. At different times, charts can be audited just to ensure that we're providing quality care, so if there's anything we should be making sure is done properly and above board, it's ending somebody's life on request.

**The Joint Chair (Hon. Yonah Martin):** Do I have time for one more quick question?

**The Joint Chair (Hon. Yonah Martin):** Yes, you have a minute.

**The Joint Chair (Hon. Yonah Martin):** Baroness Finlay, do medications used in palliative care alter a person's capacity to consent to something like MAID?

**Baroness Finlay of Llandaff:** They can do so, and we have to be really aware that morphine can make you distressed and that steroids can make you more emotionally labile.

When somebody says that they feel their life isn't worth living, you need to answer that with a question as to why, what's going on and what's happening. It may be that there is some medication there that is altering their capacity. It may be the cancer itself that's altering the capacity or the other disease they have. They may have a depression.

You have to explore it and diagnose the underlying cause. Then, when you've done that, you need to deal with the underlying causes of their distress. However, if you just respond at face value, then you'll never begin to understand the person and what they really need.

The danger is forgetting that autonomy is relational. We all interact. The way the doctor behaves towards the patient alters the way the patient receives their outcome. There's good evidence from Canada that dignity is enhanced by the way that care is given or is undermined by the way it isn't given.

● (2020)

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

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

With that, we are now officially at the end of the panel.

I would like to, again, thank our witnesses. I think we all agree here that your views were made very clear this evening in this second panel. We very much appreciate your taking the time to be with us.

With that, I will officially adjourn this committee.







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