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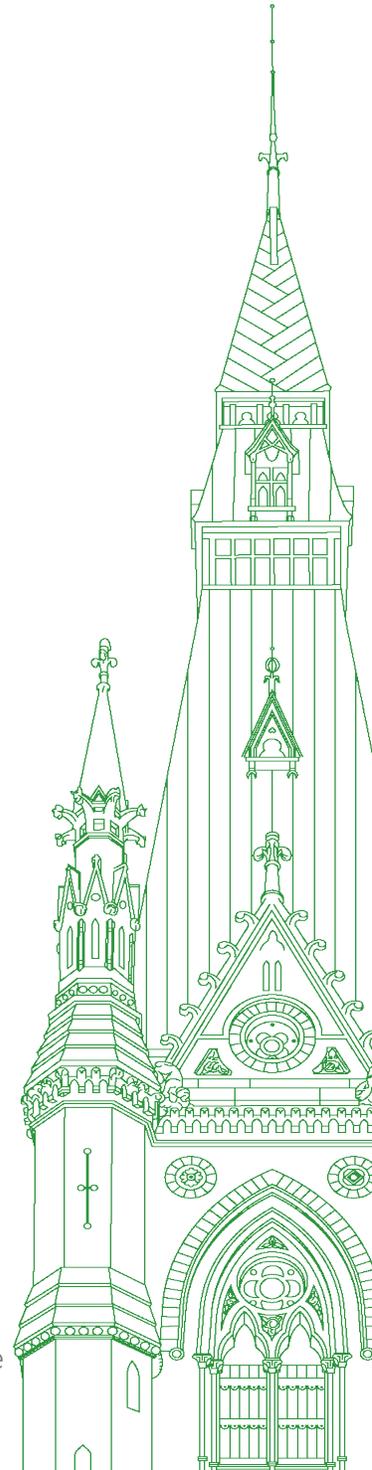
Special Joint Committee on Medical Assistance in Dying

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Co-Chairs:
The Honourable Marc GarneauThe Honourable Marie-Françoise Mégie



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• (0850)

[*Translation*]

The Joint Chair (Hon. Marc Garneau (Notre-Dame-de-Grâce—Westmount, Lib.)): Good morning. Welcome to meeting No. 23 of the Special Joint Committee on Medical Assistance in Dying. I would like to begin by welcoming members of the committee as well as the witnesses and those watching this meeting on the web.

[*English*]

My name is Marc Garneau. I am the House of Commons joint chair of this committee. I'm joined this morning by the Honourable Marie-Françoise Mégie, the Senate's vice-chair.

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

I have just a few administrative remarks.

I'd like to remind members and witnesses to keep their microphones muted unless recognized by name by one of the joint chairs. As a reminder, all comments should be addressed through the joint chairs. When speaking, please speak slowly and clearly. This is important for the interpreters. Interpretation in this video conference will work as in an in-person committee meeting. You have the choice, at the bottom of your screen, under the globe, where it says "interpretation", of floor, English or French.

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

We have Dr. Alice Maria Chung, who is a clinical associate professor, by video conference.

[*Translation*]

We have with us Dr. Judes Poirier, full professor of medicine and psychiatry at the Centre for Studies in the Prevention of Alzheimer's Disease at McGill University. He will be participating in the meeting by videoconference.

[*English*]

We have Dr. Ross Upshur, professor at the Dalla Lana School of Public Health and the department of family and community medicine of the University of Toronto, also by video conference.

Thank you all for joining us.

We'll begin with opening remarks by Dr. Chung, followed by Dr. Poirier, and then Dr. Upshur.

Dr. Chung, you have five minutes. The floor is yours.

Dr. Alice Maria Chung (Clinical Associate Professor, As an Individual): Thank you very much.

Good morning from Spain.

I'd also like to thank the IT support people for making this—

[*Translation*]

Mr. Luc Thériault (Montcalm, BQ): Excuse me, Mr. Chair.

[*English*]

The Joint Chair (Hon. Marc Garneau): I'm sorry. Just a moment, please.

[*Translation*]

You have the floor, Mr. Thériault.

Mr. Luc Thériault: Could we adjust the volume in the room? Otherwise, I absolutely have to turn the volume up to the maximum, which is not very good for my ears.

The Joint Chair (Hon. Marc Garneau): Of course, I understand.

[*English*]

Mr. Clerk, can we lower the sound level in the committee room so that Mr. Thériault can hear the translation on his headset?

The Joint Clerk of the Committee (Mr. Wassim Bouanani): Yes, Mr. Chair, it's done.

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

Dr. Chung, please resume.

Dr. Alice Maria Chung: Thank you to the IT support people, who have made this less stressful for me.

Thank you to the committee for allowing me the opportunity to address my concerns regarding advance directives for MAID in people living with dementia.

I am a geriatric medicine physician who has been looking after frail elderly people since 1989, over 30 years now. I do home visits three half-days a week for housebound seniors and I see elderly patients in hospital and in clinic. I am also the daughter caregiver for my 97-year-old father. I also helped him care for my mother, who passed away with severe dementia after living gracefully and with dignity until the age of 96. I am also involved in the care of a couple of my father's relatives who are also in their late eighties and nineties. I am professionally and personally committed to caring for those living with dementia at all stages, from early to late.

I am a firm believer in patient autonomy. If a patient is able to comprehend information on a treatment versus other options, and is able to come to a decision and communicate that decision, their wishes should be honoured, no matter how frail they may be. If they are capable of decision-making, I will support their decision. They should also, however, be allowed to withdraw consent at any time, especially when the effects may be life-altering. I teach capacity assessments to medical students, residents and practising physicians so that they will be able to identify whether a patient is capable of medical decision-making.

The issues with advance directives for MAID are several-fold. First, we are not able to predict with accuracy what our own quality of life will be in the future, let alone if we are also living with a chronic medical illness. What right does the 60- or 70-year-old you have to judge the quality of life of the 80- or 90-year-old you? Patients with chronic illnesses can often adapt to their altered circumstances and develop a new equilibrium and sense of self, and feel that their quality of life is actually quite good. The medical literature has demonstrated this to be true. I happen to have seen it in my years of practice as well.

Second, with end-stage dementia, there would be absolutely no chance to withdraw consent, which is also essential to informed consent. Someone else, a health care worker who may not know the patient, or a caregiver, would have to decide when it's time for MAID to proceed. Patients living with dementia face prejudice due to not only ableism but also ageism. It has also been shown that caregivers may not be good judges of the quality of life of their loved ones with dementia. Caregiver burden often influences the assessment by caregivers in terms of their patients' quality of life.

Finally, there is the risk that allowing advance directives for patients with dementia could lead to abuse. Patients already can face undue influence to do the right thing and not be a burden to society or to their loved ones. I have had multiple patients who have been heartbroken at having been coerced into selling their home and moving into a facility because of family pressures to not be a burden. I cannot currently protect vulnerable elderly from financial abuse with the current safeguards. I do not believe safeguards could be crafted to adequately protect them from undue influence to accept or request MAID.

In summary, I am opposed to advance directives for MAID, as people cannot predict with accuracy how they would feel in a future situation they have not yet experienced; there is no ability to withdraw consent; even caregivers of those with dementia, who know them well, have difficulty assessing their quality of life; and finally, these directives may open up another avenue of potential abuse of vulnerable elderly.

Thank you very much for listening.

• (0855)

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

[*Translation*]

I now give the floor to Dr. Poirier for five minutes.

Dr. Jude Poirier (Full professor of Medicine and Psychiatry, McGill University, Centre for Studies in the Prevention of Alzheimer's Disease, As an Individual): Thank you.

Hello to everyone who is listening this morning.

I would like to thank the joint chairs and members of the committee for this invitation. I am both very happy and honoured to have been invited to participate in the discussion with the members of this very important committee.

This morning, I am essentially wearing two separate hats.

First, I have been a researcher specializing in the causes and treatments of Alzheimer's disease for 35 years and the co-discoverer of the principal gene associated with the common form of Alzheimer's disease. I am perfectly familiar with the genetic and environmental risk factors that hide behind the disease. We will be able to talk about that at greater length if you wish, during the question period.

Second, I am the child of two parents who had Alzheimer's disease for whom I was the caregiver, first with my father and then with my mother. I followed the usual path of the fighter. I experienced the progress of the disease at every stage, up to the very end, very closely and very emotionally, and some of the fights were painful.

Although I have worked in a psychiatric hospital for 35 years and I am a full professor of psychiatry at McGill University, this morning I am talking only about Alzheimer's disease. Mental illnesses are another and, in my opinion, very different situation.

What is Alzheimer's disease in 2022?

It is, first and foremost, an incurable and irreversible disease for which the primary risk factors are genetics and age. They are both factors that it is unfortunately impossible to mitigate or manipulate with medication.

Alzheimer's disease exists in two main forms. The first is called the early-onset form; it is genetic and aggressive, and we have identified several causative genes. I stress the term "causative". It means that we know whether and when these individuals will have the disease. This small group of families represents about two to three per cent of all cases. That is not a lot, but when this form strikes a particular family, one out of every two children will become ill in each generation. If there are eight children, four of them will have the disease.

The other form of Alzheimer's disease is the sporadic form. This is probably the one you are most familiar with. You have certainly known someone, at some point in your life, who was affected by the sporadic form. This form has a genetic component that represents about 60 per cent of the risk. I am not talking about causative genes; these are risk factor genes. Unlike the familial form, it is not causative genes that are involved, it is risk genes. This risk gene will combine with factors described as environmental or lifestyle-related. They include cardiovascular problems such as hypertension, diabetes, uncontrolled cholesterol, obesity, and even uncontrolled sleep disorders. So it is the combination of genes and cardiovascular or lifestyle-related factors that trigger Alzheimer disease.

It is a disease that will last eight to 12 years, on average. At the very end, a person will gradually lose their physical and mental abilities and experience difficulty performing the activities of everyday life. In its most serious period, the immune system will deteriorate to the point that it is infections such as pneumonia or bronchopneumonia that kill the person. Alzheimer's disease does not kill the person, but it leaves the person in such a weak condition that it is the infections that kill them.

In the last two years, COVID-19 is what has killed people with Alzheimer's disease in nursing homes. It wasn't pneumonia.

That brings me to the second part of my presentation, which is an overview of the situation in the European countries that have included Alzheimer's disease in the list of diseases that may be relied on in connection with medical assistance in dying.

The Netherlands enacted a medical assistance law in 2005, but it was difficult to apply in practice for a decade in connection with mental illnesses, in particular in the case of Alzheimer's disease.

In 2018, the Royal Dutch Medical Association finally established very clear guidelines, which were confirmed in April 2021 by the Netherlands Supreme Court and allow the use of advance directives in connection specifically with Alzheimer's disease.

I am going to give you some figures that surprised me a little myself, but at the same time were reassuring. In 2018, 6,126 patients requested medical assistance in dying in the Netherlands. Of that number, 144 patients made a request when they had a diagnosis of Alzheimer's disease in the mild or moderate phase, that is, in the phase of the disease when it is still possible to make an informed judgment and give consent.

- (0900)

So 144 of the 6,000 or so applicants were given permission to receive assistance. Of that group, only two used advance directives, that is, directives that had been formally put in writing and that their families activated to respect the person's wishes. So really very few people went this route in a situation involving Alzheimer's disease.

In Belgium, people who suffer from Alzheimer's disease represented four per cent of the people who requested this assistance. Unfortunately, the data does not differentiate between advance medical directives and other requests.

In Switzerland, people with mental or behavioural disorders, including Alzheimer, represented about three per cent of the people

who requested medical assistance in dying. The figures do not distinguish between the two types of requests.

To conclude, I would like to remind you that a person does not die of Alzheimer's disease, but it certainly creates serious problems for dying with dignity. Alzheimer puts you in a severe state of physical deterioration to the point that you become vulnerable to any infection there might be. COVID-19, recently, was the one that took many Alzheimer sufferers from us.

I would remind you that the idea of psychological pain is also central to this discussion. That pain is not experienced only at the time of diagnosis; it is present throughout the illness, particularly in the second part.

I will stop here and wait for your questions.

Thank you.

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

[English]

Dr. Upshur, you have five minutes.

Dr. Ross Upshur (Professor, Dalla Lana School of Public Health and Department of Family and Community Medicine, University of Toronto, As an Individual): Good morning, honourable chairs and committee members. Thank you for the privilege of appearing before the committee today. I commend the committee for taking on the formidable tasks that are before you.

I'm a professor in the department of family and community medicine at the Dalla Lana School of Public Health at the University of Toronto, where I am also the Dalla Lana chair in clinical public health and division head of clinical public health. Additionally, I'm the associate director of the Lunenfeld-Tanenbaum Research Institute, scientific director of the Bridgepoint Collaboratory for Research and Innovation, and a staff physician at Hennick Bridgepoint Hospital, Sinai Health, in Toronto.

I've been in clinical practice for over 30 years, with a particular clinical and research interest in the care of older adults. I served on the Royal Society of Canada's expert panel on end-of-life decision-making in 2011. I was also a member of the working group on the Council of Canadian Academies' expert panel on advance requests for MAID. I'm a past chair of the Royal College of Physicians and Surgeons of Canada's ethics committee. I'm the current chair of the College of Family Physicians of Canada's ethics committee. From 2006 to 2011, I was the director of the University of Toronto's joint centre for bioethics.

The comments made today reflect my views alone and not those of any of the organizations in which I am employed or provide service for.

I recognize that public opinion polls and survey data indicate strong support for advance requests in medical assistance in dying. However, I wish to raise the following points.

As noted, I was a member of the CCA working group for advance requests in MAID. I'd like to commend the CCA and its chief executive officer and president, Dr. Eric Meslin, and the chair of our committee, Dr. Jennifer Gibson, and the members for their exemplary work. It was an illuminating experience. The process was carried out with immense rigour and thoroughness, and was as inclusive as possible in soliciting views and collecting and reviewing the evidence. It is, to my knowledge, the most comprehensive examination of the issue in existence. I do hope that members of this committee have read this report with care. As I am a signatory to the report, most of what I think is the case on the topic is in the report.

The working group represented the continuum of perspectives on the acceptability of MAID itself, let alone advance requests. There was, however, unanimity on the following points. The issues involved in advance requests for MAID are immensely complex, they are of profound importance and significance, and there are large knowledge gaps and uncertainties.

I'd like to quote from the concluding section of the report, which says, "the main issue with [advance directives] for MAID is the uncertainty faced by those responsible for following the request when it comes to gauging...whether the patient desires an assisted death." The responsibility for this decision will fall upon a third party, most likely a family member who has been designated as the proxy or substitute decision-maker, and not the physician. It's very distinct from the regime that is in place in the Netherlands.

If this becomes the case, then it is essential that the knowledge gaps identified in our report be filled as expeditiously as possible in order for there to be evidence-informed supports for substitute decision-makers, clinicians and others, because the circle of individuals around MAID is quite extensive. However, we must do this recognizing the inadequacy of current support for substitute decision-makers and the lack of uptake of advance directives and advance care planning in day-to-day practice outside the context of MAID. Much work remains to be done.

There is also considerable uncertainty around our understanding of such commonly employed concepts as suffering, and extensive clinical uncertainty as to how this is best assessed in even competent populations. This also raises questions of allocation of resources and whether sufficient resources will be devoted to ensuring that the necessary supports for substitute decision-makers and clinicians are provided, that safeguards are in place, and that there is a continuous monitoring and evaluation of any regimen put in place for advance requests for medical assistance in dying. The question of whether new resources should be brought to bear on this particular dimension of MAID when we have large extant gaps in end-of-life care is one I cannot answer but believe requires close scrutiny and debate.

Regardless of how we proceed, tough choices must be made. To paraphrase 19th century philosopher Georg Hegel, tragedy does not consist in choices between right and wrong, but between two rights.

I thank you again for the opportunity to appear before the committee. I look forward to answering your questions to the best of my ability.

Thank you.

• (0905)

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

I will now turn it over to my co-chair, Senator Mégie.

[*Translation*]

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

We will move on to the first round of questions.

Mr. Barrette, you will have the floor first.

[*English*]

Mr. Michael Barrett (Leeds—Grenville—Thousand Islands and Rideau Lakes, CPC): Thank you, Madam Chair, and thank you to the witnesses for being here today.

My first question is for Dr. Chung.

You talked about the primary caregivers of patients. I'm wondering if you can share with us why, in your opinion, primary caregivers of patients living with dementia may not always be the best judge of their loved ones' quality of life when they know them most.

• (0910)

Dr. Alice Maria Chung: Thank you very much for that question.

It does seem counterintuitive that the person who is spending most of his or her time with that patient would not be the one who necessarily knows the patient the best, but this has been shown in research.

One study that I referenced in my original statement submission was a geriatric psychiatry paper where 91 people with mild to moderate dementia were paired with their primary caregivers, most of whom were spouses or lived with the patient. They were asked to fill out a quality-of-life survey. The same quality-of-life questionnaire was given to the patients and the caregivers. Because the patients were still mild to moderate, they were able to answer questions.

There were five domains in this. One was self-esteem or how they feel about themselves as a person. Another was positive affect, which is whether they are mostly happy. Another was negative affect: Did they have anxiety, depression, sadness or guilt? Also, what was their feeling of belonging? Did they feel that they had a part in society? Did they feel that they were a part of a cadre of people who cared for them? Finally, it was the sense of aesthetics, which referred to their ability to attain pleasure in life.

They found that the agreement between the patients filling out the questionnaire and their caregivers was not very good.

Another thing they looked at was caregiver burden. They asked the caregiver how much stress they felt with their job. They also did a survey of how dependent the patients were. Over 50% of the patients needed hands-on care at that point and 44% of them had behavioural issues, such as paranoia or some aggressive tendencies. The thing that correlated the best with the disagreement was caregiver burden. If the caregiver felt extreme burden in their care, they may have been projecting their feelings onto the quality of life of the patient, whereas the patient may have felt that their quality of life was actually quite good.

I hope that answers your question.

Mr. Michael Barrett: Yes, thank you.

In cases of patients living with dementia, what are the issues in determining capacity to make personal or medical decisions such as MAID?

Dr. Alice Maria Chung: I have not done any capacity assessments for MAID, but I do capacity assessments for finances, personal decision-making and medical decision-making all the time. A lot of my patients are frail and are living with issues of potential financial abuse, as well as maybe making decisions that their family doesn't agree with. For instance, they may want to stay at home despite the fact that they're falling or they may not be eating as well. They really are able to come to a decision and say that this is where they want to be. Their decisions need to be honoured.

They obviously have short-term memory, so when you're trying to give them the pros and cons, they often have difficulty holding the information in their brain long enough to come to a decision. They have some impairment in judgment and insight, especially if the frontal parts of their brain are affected.

They occasionally have emotional lability. For instance, with a toddler, their frontal brain is not yet mature and there are these swings of emotions where in one moment they're in the depths of despair and in a minute they're laughing and happy. It can switch quite quickly. Some elderly people, especially with fronto-temporal dementia or people who have strokes in the frontal part of their brain, will have this as a problem. They're also easily fatigued, so a lot of times they cannot have an assessment in one go and you need to have multiple assessments.

Finally, they are often completely dependent on their caregiver. If someone is living with them, they're dependent on the caregiver not only for hands-on care, but also for decision-making to help them in life. This leaves them open to the possibility of undue influence. Because they have someone they are potentially insulting or going to make upset by going against their wishes, they may feel obliged to agree with them.

That's what I see a lot of times in people who tell me they want to live in their own home. They are capable, but because they don't want to make waves and they want to keep their family happy, they end up deciding to move into care. It's legal. They made the decision and they were capable at the time, but it is still very heart-breaking because that is not how they wanted to spend the end of their life.

• (0915)

Mr. Michael Barrett: Thank you.

Dr. Alice Maria Chung: Thank you very much.

[*Translation*]

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

Ms. Brière, it is your turn.

Mrs. Élisabeth Brière (Sherbrooke, Lib.): Thank you, Madam Chair.

I would like to welcome all the witnesses and thank them for being with us.

My question is for Dr. Poirier.

We are in a time of constant change. We have to adopt a position taking into account the interaction between the concepts of autonomy, suffering and vulnerability. You told us that you had two parents who had a diagnosis of Alzheimer. My mother-in-law is currently hospitalized in a nursing home; she sleeps about 23 hours out of 24. She is restrained in a geriatric chair.

You spoke a lot about Alzheimer; could advance directives also be possible for other neurodegenerative conditions such as frontal lobe dementia, for example?

Dr. Jude Poirier: Yes. I believe it can, certainly, in cases where the progress of the disease can be measured. I can tell you we are doing it in research systematically.

You know that to be able to prescribe a medication for a patient in Quebec or in British Columbia, the patient must have scored at least 21 out of 30. Then the government will pay. However, if you fall below 10, it will no longer pay. So there are scales. There is a way of quantifying these changes. My short answer is yes.

To add a bit of context, I also work, at the prevention centre I direct, with 400 children of people with Alzheimer's disease who are genetically at high risk of having the disease. The discussion we are having this morning is one I have had with them for a decade. Those situations are very relevant to what you have just raised.

Mrs. Élisabeth Brière: How can we properly oversee advance consent?

Clearly the advance request would be signed when the person is in possession of all their faculties, just as advance medical directives require in Quebec.

How can we make sure that the person has all the necessary information, that they understand the impact, the consequences, of giving that kind of consent?

The second element of my question is this: at what point would the advance consent take effect?

Dr. Jude Poirier: At the moment, I am always pleased to say, particularly to the children of people with Alzheimer's disease, that receiving a diagnosis of Alzheimer is does not mean your car is going to be taken away the next morning. That is absolutely not the case. In fact, the time has to be chosen with the family. I always say that the family has to be involved. Otherwise, we contact the people responsible for managing their finances, the lawyer, the notary, and so on. At that point, the people affected still have completely informed positions and judgments. Obviously, we cannot wait until the moderate phase to do that kind of document, so it is done at the point when it is still possible to understand the situation clearly.

On the question of activating the consent, I always have the feeling that people have gone before us. I am thinking of Holland and Belgium, that have been working on this since 2005. The Netherlands Supreme Court delivered a judgment recently, in 2021, in response to a clarification by the Royal Dutch Medical Association concerning what the ideal solution should be. There is a lot of experience and expertise there and I would put measures in place that are more or less the same as what is being done there. There is no point in reinventing the wheel in the purely Canadian context.

Mrs. Élisabeth Brière: In Belgium, as you said, they say that the point at which the advance consent is activated is when the person is no longer able to make the decision. I am thinking of my mother-in-law; she is not unconscious, but she said all her life that she did not want to live in the circumstances she now finds herself in. As the law now stands, we cannot do anything.

Following the submission of the report of the Select Committee on Dying with Dignity, Quebec seems to want to go in the same direction. Do you think this is actually the time to put advance consent into practice?

Dr. Jude Poirier: As I said, I come from the research community. It is easy for us to quantify loss of autonomy using research tools that can be simplified, and literally determine a point on a scale from 1 to 5, or from 0 to 30, and say the person has reached that threshold. From that point on, the family should be able to step in and activate the person's wishes.

That is my idea of how it should function. I particularly like the way they do things in the Netherlands, but I might add in a bit more involvement on the part of the family, so it is a little bit less completely managed by the attending physician.

• (0920)

Mrs. Élisabeth Brière: Thank you.

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

Luc Thériault will now have the floor for five minutes, like for everyone.

Mr. Luc Thériault: Thank you, Madam Chair.

The Joint Chair (Hon. Marie-Françoise Mégie): I forgot to tell the others.

Mr. Luc Thériault: Dr. Poirier, we have heard witnesses somewhat complicate the route we might take if the government allowed an individual free choice when they suffer from a neurodegenerative or Alzheimer-type disease. The people told us it was complicated, because a distinction would have to be made between happy dementia and dementia that is not happy.

What do you think about that? I imagine you can observe this "happy" condition. You are a researcher; what happens at that stage, in your opinion?

Dr. Jude Poirier: It is the child, the caregiver, who will speak.

They said that about my mom. She seemed to be in the moderate-severe phase. It was a happy dementia, because she was smiling. She didn't cause any problems. She was not a burden for the nursing home health care team. Every time I visited her, however, she asked me to find a way to end her life.

Different regions of the brain die during the course of Alzheimer's disease. It evolves differently from one individual to the next. It follows a general pattern, but the disease progresses differently from one individual to the next. The biochemical changes may resemble changes that bring on alterations in the biology of the brain, which go hand in hand. For example, the dopamine receptors play a role in pleasure and drug use. These regions of the brain die in the same way in the case of Alzheimer's disease. Chemical imbalances occur.

Are these people happy? No. My mom would not have repeatedly asked me to die. There are biological changes over which we have no control, as I explained earlier. Underestimating psychological pain is often the problem in our fine health care system. We look for physical problems and tend to see psychological problems less. I think that is where the problem lies. In research, we have tools to document it.

I'm sorry, but in my opinion, happy dementia is a strange myth.

Mr. Luc Thériault: Could we not go back upstream, for example, to when the decision is made, the point of the meeting between the care team and the person with Alzheimer? When the person needs to express their wishes, could that stage or possibility not be described, with full knowledge of the facts, and ask the person clearly what they would want to be done, if it is believed that they are in a state of happy dementia?

Is a third party not, in a way, the key in a situation like that? If the third party does not tell the care team to start the assessment, nothing gets done. I imagine the third party is not an evil person. Some people imagine that as soon as that door is opened, everyone in the health care system is going to become evil. If it is a third party, they are necessarily benevolent. So as long as the third party says nothing, the assessment doesn't start.

• (0925)

Dr. Jude Poirier: I agree entirely.

The figures from Holland impressed me, I won't pretend otherwise. I expected that 70 per cent of the 244 Alzheimer patients would make an advance request, but ultimately there were only two.

The families and the attending teams have to choose the route together. If that is the case, it will be verified with the patient when the advance request is made by asking them whether they want action to be taken if the situation arises.

I lived through it with my mother. My mother had told me she did not want any end-of-life heroic measures. That included not having an oxygen tube in her nose. I came in one morning and the nurse, who was from another culture I won't name, for whom it was horrifying not to have a tube at end of life, had decided on her own to put one in. It was a battle at the hospital to have it taken out, because the union got involved.

We see that it is being interpreted even by the care personnel at various levels. It would really have to be clear, well in advance, by involving the family and the people treating the patient in question.

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

Mr. MacGregor, the floor is yours for five minutes.

[English]

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

Allow me to echo my colleagues in thanking each of our witnesses for offering their perspectives in helping guide our committee through this study.

Dr. Chung, I'd like to start with you. In your opening statement, I think you've echoed a lot of the concerns that this committee has heard with respect to advance requests—just the idea that your future self may not have the capacity or consent abilities of your younger self, especially as the disease progresses. We do know that the word “dementia” is a scary word for many people. There is a fair amount of stigma attached to it.

However, in our last meeting, we had the pleasure and the honour of welcoming a witness by the name of Sandra Demontigny. She is living with early-onset aggressive dementia. It's a genetic version. Her father had it. She has no illusions as to what the disease is going to be like for her. She was there with her father. She watched his “descent into hell”, as she put it, and she knows that's going to be her life as well.

How do you react to someone who has such an intimate familiarity with the disease, who understands what her condition is going to be like as it progresses, and who very much is expressing her personal autonomy right now, saying, “I do not want to end up like my father”? How do we wrestle with that as a committee?

Dr. Alice Maria Chung: I think part of that is recognizing that dementia is different for different people.

Let me talk as a caregiver as opposed to a physician.

My mother was the first female obstetrician-gynecologist and the first one of Asian descent in British Columbia. She faced a lot of racism and a lot of sexism. She was a firecracker. She was not someone who would sit down and take crap from anybody.

When she became demented, we thought, “Oh my gosh, this is going to be terrible” because she lost so much of her autonomy. She was happy. I know we wonder how you can tell if someone is hap-

py if they can't talk anymore. She would sit there with her grandchildren—I'm going to cry, sorry—holding hands. She would sing. Even after she couldn't talk anymore, she would sing.

She passed away at home with my dad by her side. She had a great life. If I had asked her when she was in her full glory as a physician and a trailblazer if she would have wanted to die like that, she would probably have said, “Hell no!” At the end, though, I would say that, yes, she had a good death. She had a dignified death, and she had a happy death. It was really with the support of everybody at home. You cannot tell from how you are when you are in your fifties or sixties what it's going to be like in a situation you have not yet experienced.

There is another paper that I reference a lot of times. They had patients who were going to have—

● (0930)

Mr. Alistair MacGregor: Dr. Chung, I'm sorry to interrupt you. I only have a minute and a half left, but I appreciate your answer. Thank you for that.

Dr. Alice Maria Chung: Thank you so much. I just get passionate.

Mr. Alistair MacGregor: I totally understand. It's a difficult subject we're dealing with.

Dr. Poirier, I'd like to turn to you.

We've had other witnesses who have talked about the need to have clearly defined, objectively accessible criteria included in advance requests, especially after a diagnosis and when the disease is progressing. In your mind, if advance requests were instituted, how often should those be renewed and reviewed by the patient, the caregivers and the physicians' team? Do you have any insight that you can share with us?

Dr. Jude Poirier: Oh, boy. That's a difficult question.

I would say that it varies so much. The course of the disease varies so much from one individual to the other. Some people have had a 19-year-long decline, and I've known another one who had a four-year decline. It's very difficult.

As I said, there are certain checkpoints we know of that we could use. They're just reached faster in one case versus the other one. It could be 15 years or 11 years instead of two years. I just can't give you a decent answer on that.

Mr. Alistair MacGregor: That's fine. That's underlining the difficulty of the subject.

Thank you, Madam Chair.

[Translation]

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

I will now hand the chair back to my colleague Mr. Garneau.

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

Two senators are going to ask questions today.

[English]

We'll start with Senator Wallin.

Senator Wallin, you have three minutes.

Hon. Pamela Wallin (Senator, Saskatchewan, CSG): Thank you.

My first question is for Dr. Chung.

Did I hear you correctly when you were saying that you have no experience with doing MAID assessments, that really your comments here are about your—

Dr. Alice Maria Chung: Dementia and medical and personal as well as financial capacity—

Hon. Pamela Wallin: You've never been involved in a MAID assessment. Okay. Thank you very much.

I'll then go to Dr. Poirier.

I want to come back to this question of.... We heard from a witness recently, and this is something from personal experience as well, that we can discuss this concept of “happy” dementia. The person experiencing early-onset dementia said that this is a symptom like many others. You may feel fear. You may feel anger. You may be violent. You may be happy. These things change literally on a dime.

When people declare that other people are happy, it is a judgment from the outside, not from the inside, and it often is there to give the caregiver some sense of comfort that their loved one is happy, but if you spend prolonged periods of time with them, you will see that it comes and goes, like anything else.

How do we get around this idea, which seems to have taken root, that whatever you decided in your fifties, sixties, seventies or eighties about how you would characterize a death with dignity, somehow all of a sudden you're happy and you no longer want that? How do we deal with that issue, which seems to have grabbed hold?

Dr. Jude Poirier: Well, I think you said it right on the spot. It's a judgment call from the people around them.

I went through that with my mother. Frankly, that was a part of the progression that I did find less painful, but my mother died painfully. She died of thirst. She stopped eating shortly before she died. That's not dignity. Before that, they were force-feeding her, and then they used tubes for a while, and even that didn't work. I'm sorry, but even if she was on a dopamine spike and felt good about it, she was not dying with dignity. So—

• (0935)

Hon. Pamela Wallin: Go ahead.

Dr. Jude Poirier: No, that's my point. I'm not the only one.

The Joint Chair (Hon. Marc Garneau): I'm sorry, Senator Wallin. The time is up.

We have Senator Mégie for three minutes.

[Translation]

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

My first question is for Dr. Poirier.

Dr. Poirier, I'd like to talk about the families of your patients whose diagnosis is either genetic or sporadic. When you explain all this to them as well as you have to us today, how do they react? How do they see the future when you talk to them about medical assistance in dying? What kinds of questions do they ask you?

Dr. Jude Poirier: You met Sandra Demontigny, who has an early and inherited form of Alzheimer's.

The terrible thing about this type of Alzheimer's is that if Ms. Demontigny's father had it at age 41, she will have it anywhere from age 39 to age 43. Moreover, if her son or daughter has the defective gene, he or she will have it at age 41, 42 or 43. These individuals have a time bomb inside them and they know when it's going to go off.

Sandra is a wonderful spokesperson for people with Alzheimer's. She tells us in her own words what to expect.

Unlike others, she's fortunate enough to know when the time bomb is going to go off. So she's already been able to make arrangements for her estate and finances, among other things. She also works very hard to educate people. Individuals with the common form of Alzheimer's don't know when the time bomb is going to go off, but they're sure it will go off.

We have some tools to help us determine the course of the disease based on genetics. So far, 75 genes have been identified as risk factors. We also know that there are several environmental risk factors. We're not in the same situation today as we were 10 years ago, because we know how the disease evolves.

Personally, I tell the children of people with Alzheimer's to think about what they want to tell their families and children, including their wishes once the risk is clear.

Today, the only missing piece of the puzzle is for these individuals to be able to give advance end-of-life directives. I work with 400 people a year, and I can say that they give advance directives for all other aspects of their lives.

We've been able to educate these individuals by giving them a way to manage the situation or take control of it, to some degree.

The Joint Chair (Hon. Marie-Françoise Mégie): Dr. Poirier, I have a second question for you.

Several witnesses, including Dr. Chung, have said that people can't predict what their quality of life will be. When a person has advanced dementia, they are certainly no longer able to say that they don't want to receive medical assistance in dying or that they are withdrawing consent. We know that. Yet many people are reluctant because the patient can't withdraw consent at the end of life.

In a few words, what can you tell us about this? Should we remove the requirement to ask the person at the end of their life what they want?

Dr. Jude Poirier: That's right, because they're no longer in any condition to do so.

By the end of life, some areas of the brain have lost 70% of brain cells. For some individuals, it can be as much as 80%. The cells involved in making decisions are no longer active. So we can't ask these individuals to make decisions. It's a scientific reality.

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

We started the meeting five minutes late, but if everyone is disciplined, we have time for a second round of questions.

Senator Mégie, you may begin the second round of questions.

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

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

[*English*]

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

Thank you to the witnesses for being here.

Dr. Chung, on the study you referenced with respect to patients and caregivers, could you submit that to the committee, please?

• (0940)

Dr. Alice Maria Chung: Sure, I will.

Mr. Stephen Ellis: Thank you.

You talked about teaching capacity assessment to physicians. Can you comment briefly on how many physicians might be really good at it, and how many physicians actually are able to perform, in your experience, capacity assessments?

Dr. Alice Maria Chung: It's really a gradient, because physicians and health care workers in general do capacity assessments all the time. When you're giving someone medications or performing surgery you have to ask permission first.

Where it gets complex is when you have people with mental health issues or cognitive issues, which may affect it. Sometimes, even though I've been doing these now for 30 years, for some people I cannot say one way or the other, so the default setting is that they are capable unless they can be deemed incapable.

Mr. Stephen Ellis: That's great. Thank you for that.

Dr. Upshur, you spoke a bit about the fact that physicians should not be the ones deciding how to proceed in cases that are, as you mentioned, complex. There are knowledge gaps and there are uncertainties. I guess that leaves the decision-making to a third party.

How can we ensure, then, that there's no coercion or duress? Certainly, even with the physicians on this panel we have seen that because of their personal involvement with, I think, both of their parents, it has become a very emotional issue. How do we understand, then, that the caregivers are to make a decision for a patient without their own feelings being part of that decision-making? Obviously, looking after someone with dementia is very difficult. It's very emotional. We have seen that today.

How do we ensure, then, that they are not deciding based on their own feelings?

Dr. Ross Upshur: Thank you for the question.

I think I'll echo some of the comments made by Dr. Chung. It's one of the great uncertainties. I will direct members of the committee back to the CCA report, where we discuss in detail what needs and supports the substitute decision-makers and proxy decision-makers will need. We will not have a regimen like the one in the Netherlands, where the physician is the one who makes the assessment of the intolerable suffering and triggers the request for medical assistance in death. In Canada, it would have to come through the substitute decision-maker.

As I mentioned in my comments, we have done precious little through time to support substitute decision-makers and proxy decision-makers in making decisions in day-to-day care, let alone the weighty responsibility that it will be to trigger the initiation of medical assistance in death. We have a lot of work to do, and like many of the questions here.... Let's not wring our hands about how complex they are. Let's mobilize research resources and get answers to these questions so that we can...not eliminate the uncertainty, but actually close some of those uncertainties.

I would charge you, as a parliamentary committee, to direct the CIHR to invest resources in closing these knowledge gaps. They're considerable, and they're important. So long as there's a huge amount of uncertainty, there's going to be hand-wringing and anxiety. We need not suffer that when we're making decisions about medical assistance in death if we have the means and mechanisms to close those knowledge gaps.

Thank you.

[*Translation*]

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

Mr. Arseneault, you have the floor.

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

I'd like to thank all the witnesses, who are really providing very fascinating testimony today.

Dr. Poirier, I can't tell you how much I've learned about Alzheimer's disease, as someone who is experiencing the same stress and pain as your colleague Dr. Chung. My father has Alzheimer's and my mother died under the same conditions as yours. She died of hunger and thirst because she could no longer swallow anything. Also, three of my great aunts and great uncles, who were siblings, died one after the other. This is of great concern to me personally.

Ms. Demontigny made a big impression on all the committee members this week. On Tuesday evening, she gave incredible testimony. She was confident and had all her wits about her, so she can make a decision as important as requesting medical assistance in dying when the time comes.

That brings me to ask you a question about the 1 to 5 or 1 to 30 scale that you mentioned to help determine when one might make such a decision. I'd like you to provide some guidance. How should we, as legislators, use that scale? For example, can one request medical assistance in dying when one is at 4 or 25?

• (0945)

Dr. Jude Poirier: In research, we have that entire spectrum. We define illness in simple terms, based on three stages: mild, moderate and severe. In a slightly more specialized clinical environment, we have seven. Stages four and five are moderate. When the person with the illness reaches the severe stage, they lose their judgment. This is a critical point, the point at which, in my opinion, it happens. That's what the Netherlands experience has shown us. That's the critical point where it tends to happen.

I work with memory and judgment loss scales that go up to 70. So that moment might arrive at around 55. These scales exist. Certainly, it takes time and money to define the situation, and by that I mean levels of autonomy and intrinsic pain.

Mr. René Arseneault: I have less than 30 seconds left and I'd like to ask you the following question: What seems to be the consensus as to what people would like to see as the defining moment to request medical assistance in dying?

Dr. Jude Poirier: I'm speaking from personal experience and I can't interpret that for everyone.

Mr. René Arseneault: Go ahead.

Dr. Jude Poirier: When we see a clear and precise loss of judgment and a significant loss of autonomy, that's a signal.

Mr. René Arseneault: I have 15 seconds left.

I'd like to thank all the witnesses.

I don't have time to ask more questions, but Dr. Poirier, if you could send some information on the scales to our clerk, she can send it to all committee members. I would ask you to do that if you can.

I'd like to thank all of you.

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

I will now turn the floor over to Luc Thériault for two minutes.

Mr. Luc Thériault: Dr. Poirier, we've heard from some witnesses that we must resist offering medical assistance in dying because there may be times during the course of the illness that, even if the person has given consent and made an advance request, they may resist, refuse or something like that when the time comes to receive that assistance.

What do you think about that, that part of it where there might be some resistance?

Dr. Jude Poirier: A biological shift happens in the brain, and it affects every part of daily life, including judgment, freedom of thought and spatial perception of oneself. Basically, the brain cells die. You certainly can't compare a person's condition at that stage to what it was when they had 20, 30 or 40% more brain cells.

Alzheimer's is a neurodegenerative disease. That's why I said in my opening remarks that I didn't want us to discuss psychiatric illness at all. That's a completely different situation. I would not have the same sort of stance I had this morning.

Alzheimer's is an incurable disease; the cells die. If you do a CT scan, you can actually see the dead cells, which are shrivelled up.

Mr. Luc Thériault: Would one be required to administer medical assistance in dying anyway? Are there peaceful ways or methods of doing it?

Dr. Jude Poirier: Yes. As I told you, the scales and the method exist. After that, it's just a matter of carrying out what the individual requested in advance.

Mr. Luc Thériault: So it's more of a reflex than patients refusing?

Dr. Jude Poirier: I wouldn't describe it that way, but that's pretty much what it suggests.

The Joint Chair (Hon. Marie-Françoise Mégie): Thank you very much, Mr. Thériault.

Mr. MacGregor, you have the floor for two minutes.

[*English*]

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

Dr. Upshur, I'll turn to you.

I don't have a lot of time here, but in a previous answer you talked about our committee making a recommendation to the CIHR to close the knowledge gaps. Do you want to expand on that a bit and also maybe broaden your answer to include other recommendations you'd like to see this committee make in its final report to the federal government? Do you want to take some time to talk about that in the minute and a half I have left?

Dr. Ross Upshur: Thank you. I appreciate that.

Once again, I'll direct the committee back to the CCA report, which very thoroughly outlines almost every aspect of the discussion today and where the uncertainties lie.

Where there are uncertainties.... As you know, we have to live with a certain amount of uncertainty, but a certain amount of uncertainty can be reduced through getting the priorities of the questions and funding the research to close those gaps.

There are at least 15 different recommendations, because there's very little known. The scant evidence we have, which Professor Poirier has mentioned, is a handful of cases from the Netherlands. We've conditioned a lot about Alzheimer's and certain forms of dementia, but those aren't the only circumstances in which advance requests for MAID will take place.

I would make a recommendation that there be ring-fenced funding. I sit on one of the institute advisory boards. There are mechanisms that exist to get funding available to trigger research; plus, provincial research institutes can provide that funding.

To Professor Poirier's points, he has scales, but how valid are they? What are the sensitivity, specificity, and positive and negative predictive value? As we know from living through COVID, testing has thresholds. Here, the mistakes that we make on judging and acting on scales are irrevocable. There's quite a lot of existential weight to the decisions that are being made.

What I would like to make a really high priority is support for substitute decision-makers across the spectrum of care. Dr. Chung has spoken about the caregiving burden, not just for dementia and Alzheimer's, but for any older adult with multiple concurrent conditions. We have a crisis in elder care in Canada right now.

MAID advance requests are a small tip of an iceberg of a larger social problem. We have to ask ourselves and problematize why it is that people fear dementia so much. As everybody has spoken about, they've witnessed things they find horrifying, but why is it horrifying? Why have we created the conditions where care for dementia is so terrifying?

It's something that we created. We can rewrite that narrative through investment in care and investment in caregiver support. This kind of fearful, negative narrative that I'm hearing about is not necessarily inevitable. As Professor Poirier has said, Alzheimer's is a neurodegenerative, irreversible condition, but we can do an awful lot with social support to make this narrative a lot less despairing than what we've heard.

Thank you.

● (0950)

[Translation]

The Joint Chair (Hon. Marie-Françoise Mégie): Thank you very much, Dr. Upshur.

I'd like to ask you to send the clerk the Council of Canadian Academies or CCA report, if you could, so that it can be submitted to the committee.

I will now turn the chair over to my colleague Mr. Garneau.

[English]

Dr. Ross Upshur: If I may I speak to that, it's the CCA report that was commissioned by the Minister of Justice and the Minister of Health. This is a report that was commissioned by the Canadian government to examine the issues of advance requests for medical assistance in dying. It's a 240-page report.

You should have it, and you should read it. It covers off all of the issues we've been talking about today.

The Joint Chair (Hon. Marc Garneau): Thank you, Dr. Upshur. We do have access to it.

With that, I'd like to thank our panellists for this morning. Dr. Chung, Dr. Poirier and Dr. Upshur, thank you for bringing your expertise to bear on this very important but difficult subject. We appreciate your giving your time to us.

We'll suspend very briefly. Don't go away, committee members. We're going to start very quickly with our second panel.

Thank you.

● (0955)

(Pause)

● (0955)

The Joint Chair (Hon. Marc Garneau): Good morning to our second group of panellists.

We have the pleasure of welcoming Dr. Jonas-Sébastien Beaudry, associate professor at McGill University; Dr. Marcia Sokolowski, psychologist and philosopher; and Dr. Ellen Wiebe, medical doctor. All are here by video conference.

We'll get on with it right away.

As you know, the procedure is that you will each have five minutes to make opening remarks, and that will be followed by questions.

[Translation]

If you're ready, Dr. Beaudry, you may begin. You have five minutes.

[English]

Dr. Jonas-Sébastien Beaudry (Associate Professor, McGill University, As an Individual): Thank you very much.

I just want to express two reservations regarding the legalizing of advance directives for medical assistance in dying.

My first point is a reminder of the basic legal and moral principle that when people become unable to make decisions, such as financial or health care decisions, our law sets out protective regimes to ensure that they do not harm themselves. An important feature of such regimes is that decisions must be taken in the best interests of the person. They must be taken to foster that person's well-being. We have to provide that person with the care that is most respectful of their residual agency and most beneficial to their well-being.

At first sight, it would appear that respecting the instructions that someone gave in the past to treat them in the future looks respectful of their autonomy. However, identity, desires and needs change over time. While it may well be the case that respecting past instructions is a way to respect autonomy in many contexts, it's not obvious that it is always the case, especially when people undergo important cognitive changes. When that happens, the person may have experiences and desires that are different from those they had in the past. For instance, they have never experienced what it is to live a life with fewer cognitive capacities.

To illustrate, let's imagine a 75-year-old patient with dementia called John, who is no longer able to make health care decisions. My first point is that decisions made on his behalf should only be made for his benefit.

One may assume that, of course, John without dementia, when he was, say, 50 years old, would care about his own future self and know his future self better than anyone. That would put him in a great position to say what's best for John at 75 years old, but we could suggest that it's not so obvious. For one thing, John may not make a decision in the best interests of his older self. He may have the best interests of someone else in mind.

For instance, he might not want to be a burden on an aging spouse or other members of his family, or he might have his own interests right now in mind rather than the interests of his older, sick self. For example, he might imagine his future self bedridden and highly dependent and feel shame at the thought that this is how he would end his life and how the people he cares about would last see him.

Perhaps this evaluation seems reasonable to many people. However, such an evaluation may potentially share discriminatory beliefs about the quality of life of people with illnesses and disabilities, and about whether their lives are worth living at all. Many people live happy lives with various significant medical conditions or a high level of dependency. However, if John or anyone within his family or health care team doesn't think so because of ableist generalizations, John at 75 years old would become the victim of ableist or ageist stereotypes.

The point I'm making is that, even if you personally believe that John ought to die because you personally would not like to live if you were in that situation, we should not end John's life because you feel that way. We should do what is best for John. We should care for the patient before us, and that is John with advanced dementia at age 75. It doesn't mean that John's past preferences are not relevant. The holistic assessment of what is in his best interest may include his past wishes and preferences.

My first point is that giving the last word to the former self of a patient, sometimes a cognitively and experientially distant self, is not necessarily always respectful and beneficent towards the patient in their current state, especially if a long time has passed. If new experiences occur that the person never experienced before, if new relationships of care and dependency occur that did not exist before, if new forms of suffering and new forms of resiliency and joy are experienced that weren't experienced before, and if significant cognitive changes have occurred in the person, it makes that close connectedness between past and present selves more and more questionable, and so would be a law giving control over the fate of someone with a cognitive disability to a significantly remote past self.

If it is true that we must make a new, holistic assessment of the patient's needs, not just indiscriminately apply their past wishes, my second point is that it seems very difficult, if not impossible, to detect a kind of suffering that would justify ending a patient's life when patients themselves don't have enough cognitive capacities to express their wish to die. If the state can stay away from endorsing conceptions of lives not worth living, it should.

That second point would apply both to non-voluntary euthanasia and to an advance request law, because for an advance request to be activated, doctors would still need to be able to identify that the patient, John at 75 years old with dementia, has indeed attained the kind of suffering that would justify triggering MAID according to the patient's past instructions.

• (1000)

Thank you.

[*Translation*]

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

[*English*]

We'll now go to Dr. Sokolowski for five minutes.

Dr. Marcia Sokolowski (Psychologist and Philosopher, As an Individual): Thank you very much.

First, I wish to extend my gratitude to the chairs and the joint committee for the honour of being invited here today to discuss the extremely important topic of the use of advance directives pertaining to MAID.

By way of introduction, I'm the senior ethicist at Baycrest Health Sciences. I have a status-only position as assistant professor in the department of medicine at the University of Toronto, and I'm a fellow of Ben-Gurion University in Israel. As well, I'm a member of the MAIDHouse advisory council. However, my comments are mine alone, and I am not representing any of these organizations.

My comments are also informed by many years of being a clinical psychologist, philosopher and ethicist within health care organizations with much experience in the use of advance directives with the Alzheimer's/dementia population.

I have chaired many MAID committees and provided ethics oversight to ongoing cases. My publications include my doctoral thesis in philosophy on this topic, and a book published by Springer International in 2018 on the topic of dementia and the use of advance directives.

My academic and clinical experience portrays a range of significant concerns that arise out of the use of advance directives—and I want to say this point with distinction here—at least in the terms of how they are currently being used with the Alzheimer's/dementia population. The main question I pose is whether legalizing advance requests for MAID for those who face dementia is morally justifiable.

However, this doesn't just apply to situations where MAID is concerned, but applies equally to situations where treatments are withdrawn. Later, I will discuss suggestions to alter the conceptualization and use of advance directives in order to enhance the level and moral justification of their use.

As a number of panellists have already discussed, the dominant conception about Alzheimer's is that it's a disease of horrific tragedy and necessarily leads to loss of personhood. At least in North America, this is a very prominent conceptualization. The negative stereotype of Alzheimer's is often at the root of why people write directives in the first place, which state their desires to forgo treatment if and when dementia does strike. These directives can be especially problematic if the person with dementia is generally happy.

We also may not possess the requisite imagination or learned experience necessary to be good predictors of what we may or may not want in future situations when we offer our advance directive. Our values and our beliefs may radically change over time, and our frames of reference may alter.

Substitute decision-makers, SDMs, might also be privileging particular kinds of interest over others, not necessarily the patient's interests. SDMs do not always follow even relatively clearly expressed treatment wishes, for a variety of reasons, as my research has shown. It's problematic, therefore, to assume that having a substitute decision-maker to interpret the directive and provide the requisite informed consent generally adds any merit at all.

There is potentially tremendous subjectivity, variation and inconsistency occurring with regard to conceptualization of the advance directive in the first place, how its contents get interpreted, its intended and actual use, and how and whether it gets applied.

I also learned in my work that it would be a mistake to assume that the author of the directive behaves in a more predictable fashion. It would not be exceptional for him or her to neither expect nor even want the directive to be perceived as definitive. Rarely, however, are these expectations or wishes known to the substitute decision-maker, and even if they were, they would not necessarily prove to be the current expectations or wishes of the person with dementia.

To increase the moral nature of advance directives, not only should these concerns be rectified to the point possible, but authors of advance directives ought to be educated about the downfalls as well as the strengths of having an advance directive in order to be better informed when making a decision about whether or not an advance directive is in their best clinical interest in the long run.

I have some clinical and policy recommendations.

One, an advance directive ought to be explicitly considered as only one piece of information among many about a person's intentions and/or preferences. It is not the sole determinant of settling any medical treatment decisions.

• (1005)

Two, because an advance directive document is, at best, a weak example of the principle of autonomy, treatment wishes in any advance directive should not be construed as equivalent to or having the same self-determination status as treatment wishes made in real time by the patients.

Three, many people with dementia will still be capable of holding values, wishes and interests that matter to them. In this view, they ought to be considered to be at least borderline or partially autonomous, and medical treatment decisions should be made that cohere with them whenever possible.

Four, a directive that's very recent and doesn't seem to have been made obsolete by changes in the patient's statements, attitudes or responses to treatment can be treated simply as a current expression of their wishes. Then, in some imprecise but significant way, its status as a current expression—hence to be taken as an exercise of autonomy currently—degrades quickly with the passage of time or

the onset of attitudes or behaviour—i.e., general happiness—in tension with the content or presuppositions of the advance directive.

• (1010)

The Joint Chair (Hon. Marc Garneau): Doctor, I'm going to have to ask you to wrap up. You're past your time.

Dr. Marcia Sokolowski: Thank you very much.

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

We'll now go to Dr. Ellen Wiebe for five minutes.

Dr. Ellen Wiebe (Medical Doctor, As an Individual): Thank you so much for allowing me to talk about a subject I have thought so much about, talked so much about and am so interested in.

My experience is in assessing almost 800 Canadians for medical assistance in dying, and providing for over half of those. I was a family doctor for over 30 years, so I saw lots of dementia patients at that point. I'm a researcher and have done a lot of research on MAID, including on advance requests.

I'm going to focus the first part of my talk on the paper I sent you. I just want to make a few highlights about this.

First of all, the majority of Canadians want advance requests. A number of other researchers have found this. In our study, we asked about specific situations, as in, "Would you want to be able to have an advance request in particular situations?" Eighty-six per cent of our participants wanted it, so we're going to have advance requests. If we don't get it in 2023, we'll get it the next year, or we'll get it with the next Parliament, but we'll get it because we live in a democracy, and 86% of Canadians want it.

The specific things we talked about in our study are a loss of personal dignity, including being unable to toilet; a loss of freedom, like being kept in a locked facility; a loss of the ability to recognize family members; a loss of the ability to keep memories even for a few minutes; and a loss of the ability to control behaviour, as in becoming aggressive and inappropriate.

Now, the second really important finding of our paper was to see a gap between what people wanted and what MAID providers were willing to provide. This gap, depending on all these different specific situations, varied between 19% and 44%. Just because you make an amendment to our law, it doesn't mean you'll be able to have an advance request that is acted upon. We worked hard as a research team to look at what would make it work. We, of course, asked the MAID providers in our study and discussed it.

What would help most would be a list of very specific circumstances that are concrete in nature; readily visible to practitioners, to family members and to caregivers; stable—in dementia, it's very common for people to have, for example, sundowning, where they are fine in the morning and not fine in the afternoon—and requiring minimal interpretive judgment by the provider.

We have no experience in advance directives, but we have experience in waivers of final consent. We are finding that, first of all, patients love them. They are so grateful when they find out they don't have to worry about losing capacity before the date they've chosen for MAID. They are so relieved, and I know this is going to happen when we get our advance requests.

The other thing is that the providers actually didn't have any problem providing for the people who did lose.... In my case, I have signed many waivers of final consent. I've only used them twice, and in both cases it was just so clear. This is different, however, because I knew these people. I had assessed them. I had seen or talked to them recently. That's not the same as meeting somebody you've never seen before in a state of advanced dementia when you have to interpret everything.

What we are used to doing—and this comes to what you've just heard from the others—is taking each case separately and looking at the entire picture. I would want to see somebody who not only wrote their advance directives but had told others in the process of advancing disease that they wanted it.

• (1015)

On the question about suffering, yes, it's a big problem. If I were to see some lovely demented old lady playing with her dolls and looking perfectly happy, would I be able to end her life? I don't think so, no matter what she had said in the past.

So you're stuck. All you can do as a parliamentary committee is recommend an amendment to the law, and the law has to have the word “specific” in it, so that it is clear that an advance request is not a general one. It must be very specific. Each case still has to be assessed separately, which is exactly what we do for every MAID case when we look at the entire life of a patient and not just a few specific criteria.

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

[*Translation*]

We will now go to questions.

Senator Mégie, you have the chair.

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

Mr. Ellis will be our first speaker.

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

[*English*]

Mr. Stephen Ellis: Thank you very much, Madam Chair, and thank you to the witnesses for appearing.

Dr. Beaudry, you talked a little bit about the protection of people against self-harm and so on. One of the things that came up in one of our earlier panels was some research around the concept of suffering and how difficult that is to detect. Could you speak a bit about that, please?

Dr. Jonas-Sébastien Beaudry: Sure. Thank you for the question.

I think a key issue is that suffering is highly subjective. It's not an objective benchmark. Severe pain can be more medically objective, but suffering is not, so without the patient's input, it's simply a myth that we will not make a value-laden judgment about which life is worth living or not.

Consider, in the province of Quebec, Quebec's Bill 38, which proposes to amend Quebec's act respecting end-of-life care to include advance directives. It says that the advance request must describe in detail the physical or psychological suffering that cannot be relieved in a way that the patient would find tolerable when they write the request. Then, a monitoring system would be put in place so that when the patient shows signs of that suffering, the MAID process can be started.

The problem is that, to come back to the example I gave before, if John at age 50 is able to consent and explain that he's experiencing an intolerable suffering such that death would be preferable in his mind, that's it. Doctors, judges and legislators don't have to ask the absolutely unsolvable existential question of what is a life worth continuing. They just need to respect the fact that John made his own existential choice that it is not worth living. However, the notion of intolerable suffering cannot just be transposed onto someone who cannot make this choice, including John at age 75 with advanced dementia. That is because suffering is a complex, subjective experience.

We can measure pain. We can treat pain, and ultimately we can eliminate pain completely if nothing else works through deep sedation, but we are not talking about a response to pain. MAID has been designed and is used primarily as a response to existential suffering such as the loss of ability to engage in meaningful activities, the loss of ability to perform activities of daily living, or other fears that have to do with hygiene.

Bill 38 in Quebec says that there is a special kind of suffering. That special kind of suffering justifies MAID or euthanasia, and patients can list that specific type of suffering on their advance request. Now, the point I'm making is that I am not clear on what that suffering is, nor is the Quebec bar, which produced a memorandum last summer stating that suffering is a subjective notion, not an objective standard.

The Quebec bar's working group on MAID said that they were wondering what Bill 38 meant by this “objectifiable” kind of suffering that is observable by a doctor, the way doctors observe the symptoms of physiological dysfunctions and diseases. Presumably it means something like “objective” or “objectively verifiable”, but subjectively intolerable suffering that is worse than continuing one's existence does not seem to be objectively verifiable. There's nothing objectively verifiable about the intensely personal leap someone takes above that abyss of disagreements about the value of life, when they move from experiencing specific social and physical issues on the one hand to the decision—

• (1020)

Mr. Stephen Ellis: Dr. Beaudry, I'd like to interrupt you there. I have about a minute left. Thank you for that. I appreciate it.

Dr. Sokolowski, you talked about the substitute decision-maker not having merit in this particular process. Correct me if I'm wrong, but to me the difficulty we're coming to now is with a patient who has no capacity to make decisions on their own. Who's going to decide—a physician or a substitute decision-maker? That becomes very difficult.

We have about 30 seconds. Thank you.

Dr. Marcia Sokolowski: I think substitute decision-makers can indeed have a lot of merit. I think what's problematic is that often they don't because they're not up to date in terms of what the patient has expressed in a written or oral directive.

I think that advance care planning is a better way to go, because with advance care planning, at least the wishes and values of the patient are updated, so to speak, on a pretty regular basis so that the substitute decision-maker can really understand the values, attitudes, beliefs, specific requirements and wishes of the person.

[*Translation*]

The Joint Chair (Hon. Marie-Françoise Mégie): Thank you, Dr. Sokolowski and Mr. Ellis.

I will now give the floor to Dr. Fry for five minutes.

[*English*]

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

This is such a difficult issue. Here we are, talking about the legality, what lawyers think, what caregivers think, what families feel and think. At the end of the day, this is all about that individual person who may or may not be trapped, as we heard from Dr. Poirier, in a place where they are no longer able to make these kinds of decisions because so many of their brain cells have died. We need to stop using legal language and using a whole bunch of lingo for what, in effect, is a subjective and very important decision.

I was very moved by Dr. Poirier's testimony when he basically said that his mother begged him during the very rare times she was lucid and said that she didn't want to continue. Yet she had caregivers whose own culture and morality said that she was happy and she should continue because she was being made comfortable by them. That is very sad. I can imagine what she must, in her lucid moments, have been thinking.

Advance requests and advance directives have a certain importance. When the person has cognitive function and is able to make decisions, I think they tell us what their morality is, what their own sense of self is. We learn things from them, and as Dr. Wiebe said, you know the patient over the long term; you know who they are. So when they get to a point where they're unable to make the kinds of decisions that they would have made, you know what that person believed in, what their morality was, what their values were, what they were thinking, how they valued certain things. Making that decision needs to be done on an ongoing, long-term basis.

This is a question. I'm not making a speech, but I'm seeing the conundrum that all of us face. To say that we can make a clear, legal statement that's going to make a decision to be for everybody doesn't make any sense. This is not a generic issue. It's based on the individual person and what you knew about them before they moved into the area where they are no longer in control or people are making decisions for them with regard to advance directives.

I think we need to start going back to what the Supreme Court originally said, which was that this is about subjective decision-making by an individual person, and that may differ with different people—

• (1025)

[*Translation*]

The Joint Chair (Hon. Marie-Françoise Mégie): I'm sorry to interrupt you, Dr. Fry, but could you please adjust your microphone?

[*English*]

Hon. Hedy Fry: Is it better? All right.

I'm making this kind of statement because I do think that we are thinking as clinicians, we are thinking as family and we are thinking as lawyers about all of these things. We're not thinking about what that person is in the lucid moments, the few lucid moments—we may not even be able to talk to them in those lucid moments—when they definitely say, “I don't want to be here anymore” or “I do want to be here; I do want to continue.”

We have a really difficult problem. I think that if we try to parse this into legal constructs or into families who want their mom with them for a longer period of time and go, “Oh look, Mom looks happy. She's playing with dolls. Isn't she great?”... These are the kinds of things that we don't want to make sure the Government of Canada or the people of Canada decide for an individual human being: what their end of life should be like and what their choices are.

I don't have an answer. We're asking you guys to come and tell us because we were hoping someone among you would give us an aha moment, but at the end of the day, I don't know that this is all about us. I know that it is about that person, that individual specific person.

We heard from Dr. Poirier. We heard from Dr. Chung—

[*Translation*]

The Joint Chair (Hon. Marie-Françoise Mégie): I'm sorry to interrupt you, Dr. Fry, but I must ask that you ask your question, because you only have about 50 seconds left.

[English]

Hon. Hedy Fry: I don't have a question, Senator Mégie. I am just trying to tell you that I am still not sure what I'm hearing from everyone. I'm trying to weigh everything that everybody is saying, other than a person who is going through this and who has lucid moments and can come and tell us, "Please do not judge me from the outside or from all of the other things, legal and other, that you believe in. Let me tell you what I originally—when I knew who I was—wanted. That essential me may not have changed inside. My brain cells may have gone, but that essential me is still there. Respect that essential me."

That's all I wanted to say. I am finding this a very difficult decision panel. I am finding this whole issue extremely difficult to think about because we are all deciding for people.

[Translation]

The Joint Chair (Hon. Marie-Françoise Mégie): Your time is up, Dr. Fry.

Next, we go to Luc Thériault for five minutes.

Mr. Luc Thériault: When it comes to decisions as personal as our own death, it seems to me that the Crown has no right to decide on behalf of the patient, since it's not the Crown's life that's at stake. The Crown's role is to create the ideal conditions for freedom of choice. Since the law guarantees the principle of self-determination from our birth to our death, how can we disregard the principle of self-determination at the most personal time of life, namely the end? It's a fundamental principle.

No one has the right either to make a decision about one person's quality of life by comparing it to another's quality of life. That's another principle. So it's up to the individual, the patient, alone to ultimately make decisions about their quality of life, about what they consider to be tolerable.

Sandra Demontigny told us that she would cut her life short if we as lawmakers did not allow her to do it. This is, in fact, the spirit of Carter and of Justice Baudouin's ruling: it violates the right to life because people will tend to want to cut their lives short rather than stay alive as long as they can. I don't know anyone suffering from an illness who doesn't want to stay alive as long as they can.

So what these individuals are asking of all Canadians is that we guarantee that, on the morning they wake up and decide that life is no longer tolerable, we will let them seek help to pass on. It seems to me that it's a perfectly acceptable moral contract. It is a kind, benevolent contract, because you can't be benevolent if you're taking away someone's autonomy. These are the principles that are ultimately guiding my understanding of this debate.

What hurts in the debate we're having is the fact that a person may lose their capacity to give consent in a degenerative process. However, Bill C-7 removed the final consent requirement for those in the terminal phase of life. It's all very clear, so I don't see why we wouldn't respect a person's final wishes. We must strive to create the ideal conditions for ensuring respect for those wishes.

With this in mind, Dr. Wiebe, what can we do to ensure that those wishes are respected and that we can somehow cast aside, circumvent or dismiss the doubts we're seeing surface this morning?

• (1030)

[English]

Dr. Ellen Wiebe: Thank you.

You can't ensure that. That's what I was trying to say. It's not possible. You need to recommend an amendment to the law that allows for advance requests, because that's what Canadians want. They really want it. Most of them want it because there is such terrible suffering at the end of life that can be prevented and that some of us are horrified by. But you will not be able to actually ensure...because we have limited MAID providers. We don't have enough for our track one, which is those for whom natural death is reasonably foreseeable. We don't have nearly enough for track two, which is those for whom natural death is not reasonably foreseeable. Come March, we won't have enough for those with mental illness as the sole underlying condition, and we won't have enough for the people with an advance directive that needs to be acted upon.

But to do the best we can for the most people, I will just say that, first, the person must be very specific, and even specific about things like, "If I'm happily playing with my dolls, I do not want to continue that sort of life." Then you have to leave it to the clinicians, as you do now, and we have to take it case by case. In these kinds of cases, I will look at what the person wrote. I will try to find out what their aims in life were in general. Were they the kind of person who told their kids 20 years ago that they never wanted to live in a demented state? Were they part of this? Was this part of their whole being? That will make it easier for me to be able to provide.

You're never going to be able to fix this problem completely, but you can do what's best for the most people.

[Translation]

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

It's now Mr. MacGregor's turn to take the floor.

[English]

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

[Translation]

The Joint Chair (Hon. Marie-Françoise Mégie): Mr. MacGregor, you have the floor for five minutes.

[English]

Mr. Alistair MacGregor: Thank you to our witnesses.

It's been pretty remarkable for our committee to listen to the wide range of subjective experiences with dementia, either from clinical practice or personal familial relationships of other people who have gone through the disease. Sometimes, it's been both. We've had clinicians who are experts in dementia and who have a close family member living with it.

Dr. Wiebe, I'd like to start with you. You were talking in your opening statement about the research you've done, and surveying people's attitudes and support for advance requests and some of the reasons behind that. You mentioned a fear of the loss of dignity, the loss of freedom, the loss of memory, the inability to recognize close personal familial relationships.

Certainly the theme of stigma with dementia has been common for this committee. I know that just saying the word "dementia" for many people conjures up a lot of negative emotions.

When people were expressing their thoughts about dementia and their support for advance requests, did your research uncover any currents about what's informing people's attitudes toward dementia? Some people may not have a very good knowledge of the disease, but others have incredibly close relationships and they've been informed by that.

Do you have any other thoughts to share on that theme?

• (1035)

Dr. Ellen Wiebe: People who went into detail about why tended to be the ones who said "I watched my mother" or "I watched my aunt." They know a great deal about dementia from the outside, or inside a family but outside the person. They were very knowledgeable.

I think the people who have no personal knowledge of dementia are less likely to be interested in the subject and just want to talk and talk about it.

Mr. Alistair MacGregor: In our previous panel, the first hour of today's meeting, Dr. Upshur was referencing the state of end-of-life care in Canada and that it may also be something that informs people's opinions on dementia. He said that a lot more research and resources are needed in that.

Do you have anything to add to that?

Dr. Ellen Wiebe: These are the kinds of conversations I have every day with my patients. They say, "If I can't take care of myself in my own home, I don't want to live any longer." They talk about independence—not just quality of care, but having strangers wipe their bum. That's such a common statement. People can say they have really good care in their home, but they still have somebody else changing the diapers.

That is what people will talk about in terms of what is unacceptable, that there is no care level acceptable for that level of disability, because that level of disability is unacceptable.

Mr. Alistair MacGregor: You referenced the democratic pressure that exists—there's a very strong majority of Canadians who support moving ahead with advance requests—for our national Parliament.

If we are going to amend the Criminal Code.... You mentioned the word "specificity". How much specificity do we attach to it, as federal legislators, and how much needs to be left to the provinces? How do those work together?

Dr. Ellen Wiebe: Well, I'm not a constitutional expert or a political one. I know that the criminal law can't be as specific.... Just make sure the word "specify" is in there somewhere, so that an advance directive that just says "Kill me if I'm a vegetable" is not legal. It has to be specific, and then we'll have smart people figuring out the best ways to write those specifications.

Mr. Alistair MacGregor: Okay, thank you.

[*Translation*]

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

I will now turn over the chair to Mr. Garneau.

• (1040)

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

We will close out the meeting with questions from the senators.

[*English*]

We'll begin with Senator Wallin.

Senator Wallin, you'll have three minutes.

Hon. Pamela Wallin: Thank you very much.

I just want to comment on what Mr. Beaudry said about how advance requests that we might make at 60 would maybe make no sense to us at 75 or 80.

I just have to say that we do this all the time within the law, legally, in this country. We write wills. We leave them with lawyers. They may have been written five, 10 or 20 years ago. We have "do not resuscitate" orders. We now have final waivers of consent. There are lots of concepts around where this is practised.

The legislation I'm putting forward in the Senate now is based on consultations with people who have been part of this process for a very long time. We are proposing that there be a long list—to Dr. Wiebe's point—with very specific circumstances under which a person doesn't want to live and wants to proceed with their advance request. It's not, "I can't feed myself on Tuesday", but it's still very specific: "I am no longer able to feed myself on a consistent basis." It goes on through all of the things that she's already noted.

The other part that I think is very key to this is that the updates of this need to be regular. We've said five years. I'd be very comfortable with three. I think we have to do what gives the most people comfort on that question.

Then we come to this very important role of the substitute decision-makers. They can't just show up five minutes before this request. These people also have to be involved in the process of making sure this is updated. This is a huge commitment for people, but I think it's the only way we can do it. If you are going to be one of my two substitute decision-makers, then you are going to have to participate in this process of updating and of being interviewed by perhaps a lawyer, a doctor or another medical professional in this field. The issue is that when it comes to the provision of MAID, it may not be your family doctor. That may not be the person. These substitute decision-makers need to be very familiar with your wishes over a long period of time.

I can't think of any more safeguards that we can put in while still respecting the person's views, laid out repeatedly, about what constitutes quality of life and dignity in death.

Dr. Wiebe, do you have anything else to add to that list that I should have been considering?

Dr. Ellen Wiebe: No, that sounds good. As I said, it has to be specific enough that you'll find a provider who will actually provide, at that point.

Hon. Pamela Wallin: Yes. I realize that's an issue for everyone.

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

Thank you, Senator Wallin.

I'm sorry. Three minutes go by very quickly.

[*Translation*]

Senator Mégie, you have the floor for three minutes.

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

My question is for Dr. Beaudry.

Because you brought up two reservations and explained them earlier, would you have an additional safeguard to recommend for advance requests?

Dr. Jonas-Sébastien Beaudry: Thank you very much.

I will answer you in English, if you don't mind.

[*English*]

In terms of specific solutions, I have not yet reflected in depth on that very difficult issue here, but where I do see my own research going and what people I think would benefit from looking at is the distinction that has been drawn, for instance, by the Council of Canadian Academies between the different scenarios: advance requests made when the patient is already eligible for MAID; advance requests made after the diagnosis but before MAID eligibility; and advance requests made before any diagnosis.

For sure, the last case would be the one where my argument would apply most strongly, where the continuity between previous wishes and current wishes is no longer there. Really, it would ring some alarm bells to many people within the disability community, I gather, to hear how dignity is correlated to wearing a diaper or receiving help with hygiene care, and how we can stipulate.... Many arguments that I have just heard right now—and I find them so in-

teresting—would open the door to respecting people's autonomy, but that's my whole point: It's not the same person in meaningful ways.

If it's very recent, it's a different issue. If it's distant, we don't give anyone the power in Canadian society—not even if everybody agrees democratically or anything else—to make life-and-death judgments on the basis of potentially ableist or ageist judgments about someone whom we should care for and for whom protective regimes are usually, in our law, set up to work to protect the person, considering, of course, their residual autonomy and their past autonomy. But if we consider their past autonomy as encompassing something as specific as “when I'm not able to do X”, where that assessment would never fly if we are thinking about the welfare of someone and we are trying to think of a well-being so dismal that it calls for death, which is such an intensely personal choice that requires an ability to consent, it's a bit puzzling.

I've written on this in the case of non-voluntary euthanasia, and I think some of it applies to this case. I'm happy to forward it. Because it's such a philosophically dense topic, I'm not able to do it justice here, but I'm happy to forward that to the committee.

Thank you.

● (1045)

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

I'm afraid that time is our enemy here. We are at the end of the panel, but let me thank all of you.

[*Translation*]

I want to thank Dr. Beaudry.

[*English*]

as well as Dr. Sokolowski and Dr. Wiebe.

Thank you for giving of your time today, and in the case of Dr. Wiebe very early in the morning, I believe, as you're probably out in British Columbia.

Thank you very much. We appreciate your candour and your passionate views on this very difficult subject.

With that, this panel comes to a close.

This meeting is now adjourned.

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