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# Special Joint Committee on Physician-Assisted Dying

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## Monday, February 1, 2016

## Co-Chairs

**The Honourable Kelvin Kenneth Ogilvie**
**Mr. Robert Oliphant**

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● (1100)

[*English*]

**The Joint Chair (Mr. Robert Oliphant (Don Valley West, Lib.)):** I call this eighth meeting of the Special Joint Parliamentary Committee on Physician-Assisted Dying to order.

I hope members of the committee and others had a good weekend. I've missed you tremendously. It's been two days without you.

**Voices:** Oh, oh!

**The Joint Chair (Mr. Robert Oliphant):** I'm glad we've all survived.

In our first panel this morning, we have witnesses from the British Columbia Civil Liberties Association, the Justice Centre for Constitutional Freedoms, and Dying with Dignity Canada. Each of those three organizations will have 10 minutes to present. I'm going to suggest that we do them in that order for now.

The committee will then ask questions of all of you or any of you at any particular time.

I don't know whether both of you, Mr. Paterson and Ms. Pastine, are going to speak. You have 10 minutes between the two of you.

Thank you.

**Ms. Grace Pastine (Litigation Director, British Columbia Civil Liberties Association):** Honourable senators and members of Parliament, thank you for the opportunity to come before you today.

The BC Civil Liberties Association is the organization responsible for sponsoring and litigating the landmark Carter case. We fought that case on behalf of all Canadians who need a choice at the end of life.

Year after year, in poll after poll, Canadians have overwhelmingly indicated that they support death with dignity, and they expect to have the constitutional right declared by the Supreme Court of Canada in our case honoured by all levels of government.

You have already heard a great deal of testimony concerning the dividing jurisdictional nature of physician-assisted dying in Canada. The provinces and the territories, as you know, have primary constitutional authority over matters of public and individual health. Nonetheless, Parliament does have the power to legislate with respect to federal matters that touch on health, notably through the use of the federal criminal law power.

However, Parliament's power to legislate in this area is not unrestricted. The court did not propose or mandate the creation of a complex federal regulatory scheme to regulate physician-assisted dying. Such a law could be subject to constitutional challenge on the grounds that Parliament has exceeded its jurisdiction. More importantly, as a matter of principle, we think it is profoundly problematic to regulate the delivery of a medical treatment through the prohibitions and penal sanctions of the Criminal Code.

Physician-assisted dying is one of many available compassionate end-of-life health care options that should be available for critically ill individuals. Physician-assisted dying should be regulated in the same manner as comparable end-of-life medical decision-making, such as palliative sedation.

Every day in hospitals around the country patients make decisions to be taken off a mechanical ventilator or to refuse kidney dialysis, and those life-ending decisions are not regulated by the criminal law. That said, there are certain important matters that fall squarely within Parliament's jurisdiction.

Parliament should amend the criminal law to mirror the scope of the Supreme Court of Canada's constitutional declaration, leaving further regulation to provincial legislative authorities and the medical colleges. The court provided explicit guidance to Parliament as to how to remedy the constitutional violation. The court declared that the law is invalid insofar as it applies to a certain category of individuals—that is, it's invalid as it applies to consenting adults who have a “grievous and irremediable” medical condition that causes enduring intolerable suffering.

The Criminal Code should be amended to spell out the qualifications that would substantively entitle an individual to physician-assisted dying. In our view, there's no need to define terms beyond what is already set out in the Carter decision and understood in the criminal and the common law.

“Grievous” is a term that is already employed in the criminal law, and courts have held it to mean serious and non-trivial. “Irremediable”, as defined by the court, is a condition that cannot be alleviated by any means acceptable to the patient. “Intolerable suffering” is suffering that is intolerable to the individual concerned in the circumstances of his or her condition.

“Grievous and irremediable” should not be defined in terms of specific health conditions. It would be impossible to list the full range of illnesses, diseases, and disabilities that would meet the criteria established by the Supreme Court.

Mental illness should not be excluded as a qualifying condition. Many people who are mentally ill are capable for the purposes of making end-of-life decisions.

“Grievous and irremediable” should not be defined as “terminal illness”. The term is too vague, and it's indeterminate and arbitrary. Furthermore, there is no precise science providing a prognosis of terminal illness in terms of a specific length of time.

The Carter decision applies to a competent adult person. In other cases, the Supreme Court of Canada has cautioned against using arbitrary age limits that bear no relationship to an individual's competence to make a medical decision. We urge Parliament to affirm the principle that physician-assisted dying should rest on competence and not on age.

My colleague Josh Paterson will provide further remarks.

● (1105)

**Mr. Josh Paterson (Executive Director, British Columbia Civil Liberties Association):** Thank you.

Ms. Pastine has stated our concern about Parliament seeking to comprehensively regulate assisted dying as a matter of the criminal law, but we nevertheless wish to set out what we see as critical elements of any system to govern physician-assisted dying, whoever is doing the legislating.

The evidence accepted and tested by the courts in our case supports the conclusion that physician-assisted dying can be governed by the established norms of informed consent law, which has shown itself to be perfectly adequate as a framework for life-and-death medical decisions.

We trust physicians to do this all the time. Whether a patient is being coerced or pressed by others into a decision, whether they're ambivalent, whether they're vulnerable, or whether they're thinking clearly can all be reliably assessed on an individual basis using the procedures doctors apply in assessing informed consent and decisional capacity in medical decision-making more generally, according to the evidence before the court. No special vulnerability assessments or system of elaborate checks are needed, because the existing system for informed consent does the work that is needed.

However, this doesn't mean that there is no useful role for Parliament or the legislatures. Carter set out a floor, as you've heard many times, but Parliament is free to go beyond that in legalizing physician-assisted dying. For example, the judgment doesn't require that an individual be competent when the assistance is provided, so long as they clearly consent. We see no reason that a person who is competent cannot make a decision now for themselves later, when they may no longer be competent or no longer able to communicate. The Criminal Code should clarify that advance consent is permissible.

Turning to process, there should be no arbitrary barriers created that distinguish this from other kinds of end-of-life treatment. We advise in the strongest possible terms against instituting a review panel or other similar kind of before-the-fact mechanism, as has been urged upon the committee. This is a complete departure from current end-of-life practices. Such a regime would create an undue and totally unnecessary burden on those seeking to access physician-assisted dying, because the courts determined that physicians are entirely capable of dealing with these patient requests under normal medical standards.

Physician-assisted dying is fundamentally a private matter between the patient and the physician. This is a matter of the patient's own autonomy and self-determination. No person, no committee, and no judge should be in a position of having to approve and essentially make the decision for the patient. We've had this issue of committees before in respect of abortion, and the Supreme Court struck down those committees because they posed a barrier to access and because they took away from women their autonomy and choice over their own bodies.

Further, it's a total departure from the normal standards of consent around end-of-life decision-making to require a second opinion from another physician or a specialist. It should simply be an option, as per normal medical standards. The requirement for a second doctor could be particularly onerous in rural and northern communities.

There does not need to be an arbitrary waiting period and a reiterated request. Physicians should be able to use their own judgment, as they do in all cases in which a patient exercises informed consent in respect of an end-of-life decision. Any arbitrary waiting period runs the risk of a patient becoming incompetent in the meantime and being unable to give a second consent, or dying painfully in just the manner that they have the constitutional right under Carter to avoid. This is unjust.

Where a doctor is uncertain that a patient has capacity, there could of course be specialized capacity assessments consistent with the practice for other treatments, but neither a specialized assessment, nor a psychiatric evaluation, nor a vulnerability assessment should be a requirement for all physician-assisted dying requests, as this would be an unduly onerous barrier to access without any justification in the evidence.

As for who can provide assisted dying, as we've heard, the trial decision in Carter referred to a physician or other health care provider acting under the direction of a physician. We support the recommendation of the provincial-territorial panel that Parliament amend the Criminal Code to allow the provision of medical aid in dying by a regulated health care professional operating under the direction of a physician or a nurse practitioner.

Finally, I'd like to say a word about conscientious objection. The BCCLA stands for freedom of conscience and has fought for it regularly in the courts. As we know, physicians are not required to provide physician-assisted death. The solution we would propose is that physicians should have to notify some third party body, whether it's the hospital or the health authority, of their refusal—not provide an effective referral, but simply notify, with the permission of a patient, that they do not want to carry out this service. In that way, there can be a transfer of care for the patient.

● (1110)

In closing I would echo Professor Pelletier in his remarks that Parliament, the legislature, and the colleges may act, but they must not impose a solution that will strip this constitutional right of its meaning for people who desperately seek to die in dignity and peace.

*Merci beaucoup.*

**The Joint Chair (Mr. Robert Oliphant):** Thank you very much, Mr. Paterson.

We'll now go to Mr. Cameron.

**Mr. Jay Cameron (Barrister and Solicitor, Justice Centre for Constitutional Freedoms):** Honourable members and honourable Senators, thank you very much for the invitation to be here today.

I'll preface my comments this morning with two thoughts. The first is that I'm aware of the difficult decisions that have to be made by patients and families in palliative situations. I lost my mom seven weeks ago. We cared for her at the house, so I'm very aware, and I'm not taking a moral position with respect to physician-assisted dying or suicide.

My second thought is that despite the fact that the Criminal Code provisions against physician-assisted suicide, paragraph 241(b) and section 14 of the Criminal Code, have been struck down, the history of the medical profession remains, and it is deeply entrenched in the minds and the hearts of many physicians across the country. While the Hippocratic oath, for example, is millennia old and remains in use in various variations across North America today, it has been discarded in some jurisdictions. However, the Hippocratic oath remains in use, and it specifically prohibits giving a patient poison or counselling another person to do so. There are strong conscientious and religious objections that are held by many physicians across the country, and erasing two sections of the Criminal Code does not erase the way they feel about it and what they believe about it.

The Justice Centre for Constitutional Freedoms is an organization devoted to upholding the constitutional rights of Canadians, and increasingly these days the constitutional rights of minorities are threatened. That's typically where our case law lies.

We have five recommendations with respect to pending legislation. They are as follows.

We submit that the new federal legislation should provide explicitly that physicians, nurses, pharmacists, and other health care workers, as well as health care organizations and institutions, can refuse to participate in and refuse to refer for physician-assisted suicide.

The Supreme Court of Canada decision in Carter in no way compels doctors or other health care workers to cooperate unwillingly in a physician-assisted suicide scenario. Carter was predicated on two key factual conditions: a willing patient and a willing doctor. None of the scenarios before the court in Carter involved an unwilling doctor. The existence of a right of patients to require every physician to refer for every medical service is a misconception that some of the provincial colleges of physicians, as well as the Canadian Medical Association, appear to be labouring under. Many doctors and other health care workers object to assisted suicide on ethical, moral, or conscience grounds, or on historical grounds with respect to their profession, which does not negate the fact that their objection is one of conscience. The Supreme Court of Canada in R. v. Big M Drug Mart Ltd. made these comments:

> Freedom can primarily be characterized by the absence of coercion or constraint. If a person is compelled by the state or the will of another to a course of action or inaction which he would not otherwise have chosen, he is not acting of his own volition and he cannot be said to be truly free.... Coercion includes...indirect forms of control which determine or limit alternative courses of conduct available to others.

Our second recommendation is that Parliament should enact legislative protections for medical practitioners substantially similar to those contained in the Civil Marriage Act. In the Civil Marriage Act, specific protections were enacted for individuals and organizations that have a religious or a moral belief that marriage is between a man and a woman to the exclusion of all others. No citizen, because of the Civil Marriage Act, can be sanctioned for expressing or propagating or advocating for the belief that marriage is between a man and a woman. The legislation specifically states that it is not against the public interest to hold or advocate these beliefs, and we submit that this is an analogous situation. There is a jurisdictional overlap between the federal government and the provincial governments, and it brings this issue into line with the Civil Marriage Act situation.

● (1115)

Our third recommendation is that the new federal legislation should mandate that the application process for physician-assisted suicide should continue to be made on a permanent basis to a superior court justice. Currently applications are made to a superior court justice on an interim basis; we say that this should be permanently codified.

There are a number of good reasons to do so, in our respectful submission.

First of all, judges are schooled in the law and the Constitution. Disagreements with respect to legislative overlap and overreach can be reconciled best by a judge, who has been trained to deal with constitutional issues. Second, the courts have already said that they trust a justice to handle this weighty decision. Third, justices are capable of giving justice on a timely basis, as emergent applications to courts are regularly made, and they are regularly available in provincial jurisdictions. Fourth, the superior court justices are better equipped to handle the issues that potentially arise in a case of physician-assisted suicide. For example, there are issues of duress. There may be hostilities among family members over which course of treatment to take. Justices are used to dealing with these hostilities. In our respectful submission, it's not fair to put these responsibilities on the shoulders of a physician. Additionally, justices cannot be sued for malpractice, and they do not have malpractice insurance. We suggest that this may be an issue for physicians who make the decision to terminate somebody's life.

Our fourth recommendation is that the federal legislation should mandate a parliamentary review board to review, every three to five years, the physician-assisted suicides that have occurred and to make recommendations for legislative amendments.

I know there have been proposals that a national review body should be established and that it would be better than having a parliamentary review board. In my respectful submission, that is not the best course of action for a number of reasons. First, the enforcement of data collection and reporting would potentially be difficult for a national review board to handle, as there is no authority over the provinces. It would be difficult to bestow a national body with such powers. A parliamentary review board is already capable of doing what a national review board would be capable of doing. In addition, the national board would not be composed of individuals who are responsible to the electorate. This, of course, is not the case with Parliament. In our submission, this adds an additional level of accountability that is a requirement for issues of life and death.

Our fifth and final submission is that Parliament should note that constitutional infringements are already occurring, or are already suggested to occur, in the guidelines that are being released by the colleges of physicians across the provinces. It would be worth noting that the Canadian Medical Association has essentially said there should be a requirement to refer. It does not consider the referral for physician-assisted suicide as assisting in physician-assisted suicide. Additionally, it seeks to qualify the rights of physicians with respect to a delay component or a time component.

In our respectful submission, there needs to be a careful balancing of the rights of physicians versus those of patients, because the non-autonomous nature of a patient who requires the assistance of a physician calls into question the rights of the assistor.

Thank you so much for hearing me today.

● (1120)

**The Joint Chair (Mr. Robert Oliphant):** Thank you, Mr. Cameron.

Ms. Morris or Ms. Gokool.

**Ms. Shanaaz Gokool (Chief Operating Officer and National Campaigns Director, Dying With Dignity Canada):** Good morning.

Thank you to the parliamentary committee for inviting Dying With Dignity Canada to these hearings this morning.

We are the national advocacy organization uniquely qualified to speak to this issue. We represent the 84% of Canadians who strongly support physician-assisted dying, and our work is informed by our disability advisory council and our physicians advisory council. We are going to speak to you today about principles for eligibility, protection, and access to ensure a fully functional national framework for assisted dying in Canada.

Before we begin, we would like to address the frequent references throughout these hearings regarding the jurisdictional validity of proposed legislation.

We're not constitutional lawyers; we're concerned about Canadians. We urge that there be cooperation among the federal government, the provinces, and the territories, without which, we are deeply worried, we will be left with a provincial patchwork approach that may mean access for the most desperately ill will depend on whether their province has shown leadership in legislation.

Regarding the issue of eligibility, for us Carter sets the floor, not the ceiling. The Supreme Court stated that competent adults with a grievous and irremediable medical condition that causes them enduring and intolerable suffering should be able to access assisted death. The court agrees that only the person, the individual herself or himself, can decide if their suffering is intolerable. As we've heard this morning, “grievous” is already a term used by the criminal courts, in common language, and in common law to represent serious and very severe conditions. Therefore, we don't require any further definition. We urge this committee not to recommend a pre-approved list of conditions for assisted dying.

I'll now turn it over to Wanda Morris.

**Ms. Wanda Morris (Chief Executive Officer, Dying With Dignity Canada):** There is no issue before this committee that is more important than that of advance consent.

In their decision, the Supreme Court justices wrote that to force someone to choose between undergoing a premature, perhaps violent, death and enduring prolonged suffering is a cruel choice. We submit that unless the committee recommends that informed consent be allowed by advance consent, the injustice will continue.

Nowhere does this play out more than around the issue of dementia. In the years that I have been speaking about this subject, it's hard to overestimate the number of people who have expressed their fears, their dread, of living for years with dementia. In my home province of British Columbia, we have seen this play out in two cases, that of Margot Bentley and Gillian Bennett.

Margot Bentley was a dementia nurse. She knew that she never wanted to live in a demented state, and yet she has ended up, despite previous written wishes, in a care facility. Against her family's objections, she continues to be spoon-fed, even though she has stage seven dementia, the final stage. She is unable to communicate, is unaware of her surroundings, and has no control of her bodily functions. Perhaps in response to this, we have the situation of Gillian Bennett, a psychotherapist in British Columbia who wrote in her blog, deadatnoon.com, about her decision to end her life before her dementia left her incapable of doing so.

There is another clear case where individuals must have the right to provide advance consent to assisted dying. That is when assisted death is imminently scheduled, but after clearing all the safeguards and protocols, an individual becomes incompetent. Perhaps it's a patient who agrees with her doctor to have an assisted death on Monday but lapses into a coma on Sunday afternoon.

I now turn to the questions of safeguards and access. I remind the committee that you need to bear in mind that we must support two vulnerable populations here. There are those individuals who are socially vulnerable and may be at risk of being coerced into a death that they would not choose, and there are also those who are sick and dying, who are suffering grievously and want to ensure that they have access to this court-promised right. While doctors deal with life-and-death medical decisions every day, we accept that Canadians want to see additional safeguards in the area of assisted dying, and we believe there are two that are important. The first is that a second doctor be involved in this unique case to ensure that a patient is giving voluntary, free, and informed consent. The second is that at least initially, we believe that every single case of assisted dying should be reviewed after the fact and that there should be an aggregate review to identify any systemic issues.

We categorically reject the idea that there should be some kind of panel reviewing requests for assisted death in advance. This is not a safeguard, but a barrier. It is an obstruction to access. It would take assisted dying out of the medical realm, where it belongs, and put it in the justice system. Furthermore, in no regime where assisted dying is legalized—in Quebec, in North America, or in Europe—is this provided for. There is no regulatory support for this from the colleges, and there is no credible evidence of public support for this measure.

We do accept the premise that there are individuals who are vulnerable and that there should be protections, but why would we restrict that just to people who are seeking an assisted death? Why would we not want to also ensure that someone who is asking to be removed from life support or to stop chemotherapy or dialysis would also have a vulnerability assessment? We believe the responsibility for that should fall squarely on the shoulders of the physicians, the ones who are making decisions about capacity every day. If, as others have said, physicians are not trained to do this, we can think of no group better able to learn and to carry out this critical task.

I now want to turn to the issue of access.

● (1125)

My colleague has talked about the need of the Supreme Court to reconcile the rights of doctors and patients. Although the Supreme Court didn't compel doctors to provide an assisted death, that is not something we argue for. We believe every physician should have the right to refuse to either prescribe or administer medication, but we think it's critical that patients' rights be acknowledged too. Simply allowing doctors to turn their backs on patients and walk away does not serve patients or the health care system well.

Patients must not just be left with the Yellow Pages and information to find their own doctor. They need support and access, and we think there's a very expeditious way for the committee to recommend that this happen. It's through transfer of care. Quebec's legislation talks about a doctor notifying their institution. That would be an acceptable solution to us.

What we do not believe is that patients should be left to fend for themselves. In the event that there is not a system in place to expedite care, then the responsibility must fall on doctors to provide effective solutions and effective referral. Ultimately, the health care system must be here to support patients, not to answer to the wishes of doctors.

Finally, I'd like to talk about the roles of institutions. In the final bill in Quebec, there were some concessions made whereby stand-alone hospice palliative care facilities were allowed to choose not to provide an assisted death. We have also heard from many religiously affiliated institutions that they do not believe that assisted death should be provided on their premises.

We do not accept that bricks and mortar have a right of conscience. If a taxpayer-funded institution has patients who are eligible for assisted dying, they must provide it. It is not up to them to deny patients their charter right, nor can they discipline doctors who are acting on their conscience to provide a qualified patient within the framework of the law with the right to the assisted death they seek.

We remind the committee that your decisions and recommendations will affect how Canadians die for decades to come. We urge you to consider two core Canadian values: that of compassion, and that of patient autonomy, or what we call choice.

Thank you.

● (1130)

**The Joint Chair (Mr. Robert Oliphant):** Thank you to our five witnesses for your presentations this morning. My co-chair is always pleased when you're right on time, and we're both always pleased when it's so thoughtful. Thank you.

For questioning, we first turn to Ms. Dabrusin.

**Ms. Julie Dabrusin (Toronto—Danforth, Lib.):** My first question is for Mr. Paterson.

Could you please comment on Mr. Cameron's suggestion that it would be best to continue to refer cases to courts to decide whether a person should be allowed to have physician-assisted dying?

**Mr. Josh Paterson:** Thank you for your question.

We are completely opposed to the proposition that there be a requirement for any sort of prior approval that goes beyond a patient and their physician coming to a decision on treatment, and of course it's the patient who will be making the decision and the physician who is going to provide the treatment.

We think it's a violation of people's privacy rights. It's completely different from anything we do in other kinds of end-of-life care. It's not the standard that's been used almost everywhere around the world but for one country, and there our evidence is a little scanty, as you will remember from a few meetings ago.

We do not endorse that. In fact, we quite oppose it. Also, we think that has a great potential to put in place barriers that for some people may be insurmountable, not only in rural and northern areas but also in cities. As I said earlier, we've seen these kinds of barriers before in relation to medical decisions that really should be autonomous decisions for a patient.

**Ms. Julie Dabrusin:** Thank you.

You suggested a system when we were talking about conscience rights. You were suggesting a system whereby a physician would be able to tell a third party that they had objected.

**Mr. Josh Paterson:** Yes.

**Ms. Julie Dabrusin:** It would be simply that they had objected. Could you flesh that out a little more as to how that system would look? Who would be this third party? What would that look like?

**Mr. Josh Paterson:** This, we think, is actually a matter for the provinces, because it's about regulating access. Quebec provides an excellent example. Essentially we endorse the model that Quebec uses. In Quebec it's a local health authority. It would be up to provinces to figure out the appropriate body to notify. Perhaps it would be the hospital, or another body could be designated. In British Columbia we have regional health authorities.

The key is that the body would then be under an obligation to contact, as quickly as possible, the patient who has given consent for that information to be transmitted to them. That body would then be in charge of setting the patient up with someone who can provide the service. It gets the doctor out of having to make an act of referral. They simply have to tell someone that they're refusing.

We don't think that's too much to ask. The interest in conscientious objection is a carefully qualified interest. It isn't absolute. We think that forcing a physician to engage in an act of referral would be going too far, but this is an accommodation that would serve everyone.

● (1135)

**Ms. Julie Dabrusin:** Okay. Thank you.

You mentioned there is a privacy issue about the patient having to give consent for that information to go to the third party. Do you foresee any stumbling blocks in that connection? Is there anything we should be watching for in that part of the procedure in order to ensure that there's proper information available for the patient?

**Mr. Josh Paterson:** We think it would be a matter of simply asking the patient. Presumably the patient is in a conversation with the doctor who is refusing, a doctor who, under the norms of informed consent, would have had to provide information about the treatment. We would not excuse doctors from that obligation.

It would simply be a matter of saying to the patient, “May I indicate my refusal to this body?” If they say yes, then the doctor can do that. If they say no, then the doctor doesn't have the permission to make that indication.

**Ms. Julie Dabrusin:** All right.

**The Joint Chair (Mr. Robert Oliphant):** You have 30 seconds.

**Ms. Julie Dabrusin:** Okay. I'll be quick.

Ms. Morris, when I looked at the legislative framework that your organization put forward, I saw a system for mandatory referrals. You restricted it to physicians and pharmacists in that framework. Why is that?

**Ms. Wanda Morris:** We believe that ultimately a patient should have an effective referral, but if that can be accomplished by a transfer of care, we're happy to work with others to achieve a reasonable result.

I'm not sure where it says that it's just physicians and pharmacists. We saw the two potential stoppages as a physician who wouldn't refer or a pharmacist who wouldn't fill a prescription, but certainly we think no health care professionals should be able to obstruct the process.

**The Joint Chair (Mr. Robert Oliphant):** I think I have to cut you off here. We may ask for a written response if we need a further answer. Thank you very much.

Mr. Cooper.

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

My question relates to mature minors. It's directed to the BC Civil Liberties Association as well as to Mr. Cameron.

If the Supreme Court contemplated mature minors—persons under the age of 18—having euthanasia or assisted suicide available to them, why would the court not simply have said so? Instead, the court repeatedly—at paragraph 68, paragraph 127, paragraph 147—referred to a competent “adult person” as opposed to a competent “person”. Indeed, when you look at paragraph 111 of the decision, the court went so far as to say that euthanasia for minors “would not fall within the parameters suggested” by the court.

I'd be interested in your comments.

**Ms. Grace Pastine:** Our position is not that the Supreme Court of Canada has made any pronouncements on the availability of physician-assisted dying for mature minors. It has not. It has in previous situations reflected on and ruled on the ability of mature minors to make health care decisions.

This is a distinction between Carter setting a floor and Parliament being able to raise the ceiling. We agree with you that the Carter decision refers to competent adult persons. Certainly there wasn't evidence before the court about making physician-assisted dying available to mature minors. That said, we recommend to Parliament that Parliament affirm the principle that physician-assisted dying ought to be available to mature minors, because that's in keeping with laws across Canada that have established that individuals under the age of majority have the right to make health care decisions when they are competent to do so.

● (1140)

**Mr. Jay Cameron:** Thank you for the question.

My position is twofold. First of all, the idea of mature minors is, to a certain extent, oxymoronic. They require litigation guardians for all sorts of civil actions in our society, and we don't trust them to litigate on a number of issues. They're growing. They're learning about themselves. They are subject to sometimes unreasonable depression.

There is a reason the court mandated that physician-assisted death was for competent adult persons. There are two components of that. One is competence, and one is adulthood. It appears to me that there are very good reasons for that.

**Mr. Michael Cooper:** My next question is for Mr. Cameron and the BC Civil Liberties Association witnesses.

The court repeatedly refers to “those who seek assistance in dying”. It's in paragraphs 69, 98, and 106. As I read that, and as the court puts it, it would seem that what the court was saying was that the patient must seek assistance in dying, as opposed to a physician, for example, offering suicide. What are your thoughts?

**Mr. Jay Cameron:** If I understand your question correctly, you're referring to the difference between counselling a person to commit suicide and the patient asking for suicide.

**Mr. Michael Cooper:** That's correct. In other words, the patient is the one who would clearly have to go to the physician. It would not be the physician, for example, listing a menu of options that might be available to the person. Do you see the distinction?

**Mr. Jay Cameron:** Absolutely, there is a distinction. When people face hardship and extremely difficult circumstances, the suggestion that the best thing to do or that one of the options is to end their life can take roots of its own, I think.

Irrespective of the reasoning behind the recommendation, it can become coercive. These proceedings aren't happening in a vacuum. They're covered in the media. People are aware of what's happened in Carter, and people are aware that on some level there is a right, as stated by the court now, to seek physician-assisted death.

**The Joint Chair (Mr. Robert Oliphant):** Thank you, Mr. Cameron.

I know that others want to get into that. I'm afraid you're not able to, but you can throw it in later, if you want.

We'll turn now to Mr. Rankin.

**Mr. Murray Rankin (Victoria, NDP):** Thank you. I'll be sharing my time with Ms. Sansoucy.

I want to thank everyone for being here. We have a very limited amount of time, so I'm going to jump right in and ask the witnesses from the BC Civil Liberties Association about the issue of vulnerability.

You very powerfully presented the issue of access, and Mr. Paterson talked about vulnerability in two contexts that I want to explore with you.

The first was that no waiting period should be required. We've heard testimony about how, after a debilitating injury, it seems that a lot of people—the majority, we've been told—who contemplate suicide have deep depression, so the argument would be that a serious waiting period would help to protect the vulnerable in those difficult circumstances.

The second point you made was that there should be no requirement, you argue, for a second doctor's opinion, yet you have said that a nurse practitioner or a doctor might in certain circumstances provide this and confirm consent. Would it not be terribly onerous to provide that second opinion from another doctor via telemedicine?

I'd like your comments on both issues.

● (1145)

**Mr. Josh Paterson:** Thank you, Mr. Rankin.

In terms of a waiting period in the situation of someone who has suddenly been injured and who feels as though they don't want to go on any further, I would echo what Professor Downie had to say a few meetings ago, which was that informed consent law and the practices that doctors already use in determining whether someone has the capacity to make a decision and whether they are consenting in an informed way already deal with that. It's open for doctors to say, “You know what? I'm not sure you are quite grasping the situation you're in right now” and to use their own judgment, according to the authority that's regulating them, to work with a patient on those issues. We don't see it as being a problem. Conversely, we see putting a waiting period in place as having the potential to create a lot of harm.

The second question had to do with the second doctor and whether there was telemedicine and whether we could make this easy and maybe have an app or something that one could use. We think that regardless of the technology, regardless of whether you can put together a facility that would allow a second doctor from a big city to provide a second opinion for someone living in rural community, it's just inconsistent with other end-of-life practices to have it as a requirement. Sure, if the doctor feels that he or she would benefit from the judgment of another professional, then by all means we think it's open for a doctor to seek that out, as doctors already do for other end-of-life decisions. For us it's more about keeping this consistent with other end-of-life practices than it is about the technology.

**Mr. Murray Rankin:** I'm not sure how much time I have, Mr. Chair, but I would like to ask one quick question and then perhaps turn it over to Ms. Sansoucy.

**The Joint Chair (Mr. Robert Oliphant):** You have two minutes.

**Mr. Murray Rankin:** This has to do with the issue Ms. Pastine referred to concerning advance declarations. The Carter criteria describe enduring suffering intolerable to the individual in the circumstances of his or her condition. I'm thinking of Alzheimer's disease and the issue of dementia that Wanda Morris of Dying With Dignity referred to. By definition, the person would not be suffering or would not have the kind of enduring suffering, perhaps, if they were unaware that they were in pain. They're not in pain if they have dementia at the end of life. They might provide an advance declaration for that.

I take your point about ceilings and floors, but I wonder if it's open to us, in faithfully applying the Carter criteria, to address dementia as you've described.

**Ms. Grace Pastine:** I think it would be open to you, and we would, in fact, recommend that if your interest is making advance directives in the area of physician-assisted dying available to patients, that you explicitly set that out in federal legislation, because that would modify the consent requirement, the consent parameters, that were set out by the Supreme Court of Canada in Carter. It's possible my colleague, Mr. Paterson, would like to—

**Mr. Murray Rankin:** I appreciate that, but I wonder if I could ask Madame Sansoucy.

[*Translation*]

**Ms. Brigitte Sansoucy (Saint-Hyacinthe—Bagot, NDP):** Thank you.

My question is also for Ms. Pastine.

In some U.S. states—such as Oregon, Washington, Vermont, California and Montana—assisted suicide is permitted, but voluntary euthanasia is not. However, the Netherlands, Belgium and Luxembourg permit both assisted suicide and voluntary euthanasia. Voluntary euthanasia is permitted in Quebec, under the Act Respecting End-of-Life Care.

Could you tell the committee what your interpretation of the Carter decision is on the matter. Does the decision prompt Canada to permit both voluntary euthanasia and assisted suicide?

**The Joint Chair (Mr. Robert Oliphant):** Ms. Pastine, you have 15 seconds.

[*English*]

**Ms. Grace Pastine:** Thank you for your question. Absolutely the Supreme Court of Canada's decision mandates assisted suicide and euthanasia. Our position is that it's absolutely inconceivable that the court's decision could be interpreted in any other way.

**The Joint Chair (Mr. Robert Oliphant):** Thank you.

Senator Seidman.

● (1150)

**Hon. Judith G. Seidman (Senator, Quebec (De la Durantaye), C):** Thank you very much.

You've all talked about the right of conscientious objection for the physicians, and clearly the question that comes forward is what the best means is to assure equity and access to assisted death for patients who want it while reconciling that with the charter rights of physicians with regard to conscientious objection.

The CMA, in their 2015 report on this subject, called for the creation of a separate central information, counselling, and referral system, and I'm wondering what your reactions would be to that approach. I put that question to all three of you.

**Ms. Wanda Morris:** Our primary concern is that patients not be abandoned. If that recommendation effectively allows for care to be transferred and patients to receive treatment, then we support it.

We do have concerns, though, about an independent agency being able to carry out that function without access to confidential information about who is providing assisted deaths. Also, we're really concerned that this shouldn't be outsourced outside the medical system so that an independent group perhaps would have to fundraise to provide that critical service.

**Hon. Judith G. Seidman:** Mr. Paterson.

**Mr. Josh Paterson:** Thank you.

I'd echo everything that Ms. Morris just said.

I would simply add that whatever body is there would have to have the capacity to respond quickly. There can't be backlogs or situations of “We're not going to get to it this week.” This needs to be done fast. Whatever agency is there has to have a really robust responsibility to put the wheels in motion to ensure that patients can get the care they've asked for.

**Hon. Judith G. Seidman:** Mr. Cameron.

**Mr. Jay Cameron:** I think that such a response is effective. I think it's favourable. If it is properly implemented, I think it's the best solution.

**Hon. Judith G. Seidman:** Mr. Paterson and Ms. Pastine, in your presentations both of you said that physician-assisted dying basically should be treated like any other medical decision and should be governed by the established norms of informed consent and competency assessments.

In that case, I would like you to go through the steps, as you see them, that should be involved in making a request for physician-assisted dying and then for the physician to respond to that request. In very concrete, pragmatic terms, how do you see that happening?

**Ms. Grace Pastine:** As you say, we see physician-assisted dying as part and parcel of compassionate end-of-life care. Our position is that it should be treated no differently from withdrawing or withholding treatment or providing palliative sedation.

If a patient—for example, an individual who is suffering from ALS—wanted assistance to die with dignity, we would expect that they would make their desire known to their doctor and that their doctor would make sure they were fully informed of all their available end-of-life options. We would expect that they would be fully informed about their prognosis and their diagnosis, etc., and were made aware of the existence of palliative care and other options available to them. This is in keeping with standard medical practice.

A doctor may have a pre-existing relationship of over a decade or more with a patient and may know the patient's views well, but if the doctor had any concerns about the patient's capacity, any concerns about the patient's ability to make an informed voluntary decision free from duress, keeping in mind that in many situations those concerns won't exist, the doctor would then, in keeping with normal medical practice, refer that individual for an individualized capacity assessment. That could mean referring the patient to another doctor or to a psychiatrist or a specialist in geriatrics. There are a variety of ways in which doctors are able to seek capacity assessments.

● (1155)

**The Joint Chair (Mr. Robert Oliphant):** Thank you, Ms. Pastine.

Senator Cowan.

**Hon. James S. Cowan (Senator, Nova Scotia, Lib.):** Thank you for being here this morning. It's very interesting.

I'd like to return to the issue of advance consent or advance directives and the concern that I think we all share about exposing vulnerable people to results that they would not want if they were to change their minds. I think particularly about people with advanced Alzheimer's. As I understand it, the suffering that we talked about doesn't have to be pain; it can be a condition.

I'd like you to take me through how you would see this working in practice, using the example of somebody with advanced Alzheimer's. We may have a situation whereby at the time they formulate this directive, they're clearly competent in every way, but they're looking ahead to the date when they might not be competent. How do we assure ourselves, as best we can, that their interests are really being protected?

**Ms. Wanda Morris:** I think that what we do will actually be life-affirming if we are able to provide a clear advance consent mechanism.

First of all, we're talking about a situation in which someone has already been diagnosed. They are living in the reality of their diagnosis of dementia and are giving free and informed consent in that way. Second, I believe we would have something like a single-purpose form that clearly states, in relation to their condition, the criteria upon which the suffering, to them, would be such that it would be more harmful to be kept alive than to be assisted to die.

**Hon. James S. Cowan:** It would be through the eyes of the patient.

**Ms. Wanda Morris:** Yes. For example, although the patient might realize that many people in early stages of dementia have much in terms of quality of life, the patient might not want to live in certain situations. They may say, "When I am bedridden; when I can no longer feed, wash, and shave myself; when I have been unable to speak for a period of 30 days or more, at that point, please give me assistance to die." They lay out objective, verifiable criteria. Then a doctor who chooses to do so—because doctors would always have the right of conscientious objection—would provide an assisted death.

The form, the paperwork, is a single-purpose document that is done ahead of time. It is subject to the same safeguards as a contemporaneous request, but the individual is able to be assisted to die at the end.

**Hon. James S. Cowan:** Ms. Pastine, Mr. Paterson, can you comment on that issue? From a practical point of view, how would this regime work to assure the kind of protection that we all want to have?

**Mr. Josh Paterson:** I'm afraid, Senator Cowan, I don't really have a lot to add to what Ms. Morris has said. I would echo the things she's said.

The provincial–territorial report has also set out, as I'm sure you all know, some different scenarios that I think we can draw from in informing ourselves about this issue.

For us, the key is that we just don't see any really relevant distinction between someone consenting now and someone giving advance consent. We don't want people to be trapped, in a sense, in the suffering they would have to liked to avoid, and could have avoided, by an advance directive.

**Hon. James S. Cowan:** This is even if there's a loss of competence between the time the document is executed and the time the assistance is provided.

**Mr. Josh Paterson:** That's exactly the kind of scenario in which we would say you would need an advance directive: to ensure that someone who does lose competence is still able to have their wishes in this respect carried out. We think that's important.

**Hon. James S. Cowan:** Ms. Pastine.

**Ms. Grace Pastine:** I agree with what Ms. Morris and Mr. Paterson have said.

I mean, it's in those situations of a person no longer having capacity that you would need to have a provision that a patient can provide advance consent. A patient can always override a previous decision. If they have enduring capacity, obviously they can change their mind, but we believe that advance care directives are very important in terms of preventing unnecessary and unwanted suffering.

● (1200)

**Hon. James S. Cowan:** Do I have time?

**The Joint Chair (Mr. Robert Oliphant):** You have 15 seconds.

**Hon. James S. Cowan:** I'll pass. I'll give 15 seconds to someone else.

[*Translation*]

**The Joint Chair (Mr. Robert Oliphant):** Mr. Arseneault, the floor is yours.

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

I also want to thank the witnesses for their presentations.

It is important to hear what you have to say because you will help this committee make a decision with regard to the Carter ruling, which has already indicated what the finishing line is. So we have to permit physician-assisted dying within the parameters set by the Supreme Court of Canada. The committee is tasked with deciding how to do that.

My first question is for Ms. Pastine. It is actually in the same vein as the question asked by our colleague Ms. Sansoucy. So I would like to hear your answer.

Considering the Carter decision, how do you view physician-assisted dying when it comes to the two options we often hear about—assisted suicide and voluntary euthanasia?

[*English*]

**Ms. Grace Pastine:** Assisted suicide and voluntary euthanasia are both covered by the Carter decision. An example of assisted suicide would be the case of a patient who is prescribed life-ending medication by a doctor and then that patient self-administers the medication. In some situations an individual will be incapable of doing that or may simply prefer to have the assistance of a doctor, and that's why in certain contexts, voluntary euthanasia would be the preference of patients, and, frankly, of doctors as well.

The term used to describe both of these types of end-of-life care is physician-assisted dying. That was the term that was explicitly defined by the B.C. Supreme Court. As well, the Supreme Court of Canada, in striking down both section 14 and section 241(b), made it clear that it's referring to both of those practices. I should add that at no point did the government in the Carter case take the position that a constitutional violation applies to one form of end-of-life care and not to another. That's why I say it is simply inconceivable that the court's decision could be taken to mean anything other than that the criminal prohibition against physician-assisted dying, as I have defined it, is unconstitutional.

[*Translation*]

**Mr. René Arseneault:** Thank you very much, Ms. Pastine.

My next question is for Mr. Cameron.

Mr. Cameron, we are familiar with the background of the Carter decision and know that the lead plaintiff travelled abroad to seek assistance to die, knowing that the legal system would not respond to her request before she died.

You said that, in your opinion, in order to maximize safeguards for the most vulnerable individuals, the justice system—in other words, a superior court—or judges would have to have the power to determine whether someone has the ability to ask for assisted suicide.

The provinces have different superior courts whose judges do not often or always hand down the same decisions on the same issue. That is why courts of appeal exist. By the same token, provincial courts of appeal do not always render similar rulings in identical contexts, and that is why we have a Supreme Court.

How can you reconcile your restrictive stance with the spirit of the Carter decision given the context of that ruling?

[*English*]

**Mr. Jay Cameron:** Thank you for the question, sir.

I can lean on my own experience here to say that there are doctors and there are doctors. Just as there are judges and there are judges, there are doctors and there are doctors, and when you aren't able to find medication or obtain medication from one doctor, you are often able to find it from another doctor. That's why you "doctor-shop".

The protection of having a superior court justice is that it is someone who is removed from the situation of the physician, someone who can weigh the law and the affidavits of physicians and the competing evidence from family members and make an informed and legal determination. There is no doubt that sometimes judges get the answer wrong, but it seems to me that as far as ethical considerations go, it is far better to have the matter in the hands of a judge than in the hands of a physician.

● (1205)

**The Joint Chair (Mr. Robert Oliphant):** You have 10 seconds left.

We are a little bit over our time, but I'm going to have Mr. Warawa ask some questions now. Knowing that the next session has only two panels, we'll make up the time then.

Mr. Warawa.

**Mr. Mark Warawa (Langley—Aldergrove, CPC):** Thank you, Chair.

MP Aldag and I had a town hall meeting on Saturday, which was very informative. The term "physician-hastened death" was shared as a more appropriate term. "Physician-assisted dying" was seen as being very general. That was what was suggested by a number of people, so I'm going to use that term, because I would agree that it is a more accurate term.

Interestingly, as I was reading on the plane on the way here, I was sitting beside a physician with the Royal College of Physicians and Surgeons, who is here testing specialists to determine whether they have the qualifications to practise as specialist surgeons and physicians in Canada.

I went onto the website and found that they, as physicians, are having a dilemma on this issue and on how to deal with it, so I would think Mr. Cameron is quite right in saying there are physicians and physicians. There are diverse opinions on this issue.

The Supreme Court said that we are mandated to create a carefully designed system that imposes strict limits that are scrupulously monitored and enforced.

One of the suggestions we have heard around this table, Mr. Cameron, is that an advance directive later in a person's life, when he or she is no longer competent to make that decision, would be binding on them. I'm not sure how long an advance directive would be. You are suggesting that a superior court should have the final say, in a timely fashion, so that a person would have the right to end his or her life. However, the Supreme Court decision was that it should be a competent adult. If somebody has the opportunity to end their life through physician-assisted suicide or voluntary euthanasia, meaning that a physician would introduce the drug, and the person is competent enough, at the point of death, to end their life, would you see an advance directive as diverging from this requirement to have a strict regime enforced and monitored if you do not have consent at the point of death?

Thank you.

**Mr. Jay Cameron:** Thank you for the question.

I do, absolutely, and there are two components to my answer. I'll be brief.

The first problem with advance consent is that if there is an issue of duress in advance, then after the person has become incompetent, you essentially can't figure that out, so if there is a problem with duress or there is some other family issue, by the time the person becomes incompetent, you can't go back, because you can't ask them anymore. You can't take them into a room separately and ask, "Did you really want to do this back then? How do you feel about it now?"

The other part of my answer is this. My wife and I care for her father, and he has advanced dementia. I don't know what he would have said if he had known this was going to happen, but there is a difference between making a decision that eventually you want to die and what you may feel when you're actually in the moment. He seems to be enjoying life, so would he want to make that same decision if he could go forward in time and vocalize it? When you have said that you would want to die, there is no point of reference to know whether in the future, when you are in those circumstances and have dementia, you're actually going to be so sick of life that you actually will want to die. That is the problem inherent with an advance directive.

**The Joint Chair (Mr. Robert Oliphant):** We're going to suspend for a brief moment while we change the panellists. We'll recommence in two minutes.

● (1205)

(Pause)

● (1215)

**The Joint Chair (Mr. Robert Oliphant):** I call the meeting back to order.

We have two sets of witnesses: Dr. Francine Lemire, of the Collège des médecins de famille du Canada, and the Alzheimer Society of Canada, which is joining us by teleconference.

I'm going to begin with Dr. Lemire for 10 minutes, and then give 10 minutes to the Alzheimer Society.

Dr. Lemire.

**Dr. Francine Lemire (Executive Director and Chief Executive Officer, College of Family Physicians of Canada):** Good afternoon. As mentioned,

[*Translation*]

my name is Francine Lemire. I am the Executive Director and Chief Executive Officer of the College of Family Physicians of Canada. I am a family physician myself. I want to thank you for inviting me. It is a privilege to be presenting to you today.

[*English*]

That is as much French I'm going to use in the presentation, but I will be pleased to entertain questions in both official languages. I'm glad that I'm here now, because judging by the lunch you're having, you may be quite sleepy this afternoon. You need to be thinking about that.

**Voices:** Oh, oh!

**Dr. Francine Lemire:** I'm also glad that I was here for the first part of this discussion, which has given me the flavour of the kinds of questions we may be discussing.

The College of Family Physicians of Canada represents 35,000 members across Canada. We are the professional organization that is responsible for establishing the standards of training and certification for family physicians. We also accredit continuing professional development programs, enabling family physicians to maintain certification in family medicine and meet licensing requirements regarding their commitment to lifelong learning.

We accredit the postgraduate family medicine residency training in each of Canada's 17 medical schools. We provide quality service, support family medicine teaching and research, and advocate for family physicians and the patients they serve.

As the voice of family medicine as an academic discipline, we are expected by physicians to reflect on and express an informed approach, expectations, needs, and concerns on important issues such as physician-assisted dying.

After listening to the first part of the presentations, I could say that my remarks could probably be summarized by saying that we believe it is important that this discussion be part of the context of a patient-physician relationship and not be purely a process-focused exercise. I'm not saying that process is not important, but I would say that the context of the relationship and how that fits is probably the most important element of this discussion.

In 2013 the college established a task force on end-of-life care. It examined ethical issues on which family doctors might require further education and guidance. The task force recently released a guide that addresses key ethical questions family physicians may have as a result of the recent changes in Canadian law affecting physician-assisted dying. This guide has been shared with the committee. I'm assuming that you can refer to it in your deliberations.

In these difficult situations, as in any clinical decision-making process, family doctors are responsible for ensuring that our patients have all the relevant information to make the most informed and consensual decision regarding their care. A patient's medical diagnosis, their prognosis, what their life expectancy is, the potential risks and consequences associated with treatment or the withholding thereof, as well as the procedure that would result in their death, are just a few examples of information that a patient will need. Because it is a component of comprehensive care that our members offer, family doctors will ensure support is available for the patient's family or other caregivers. The family physician will educate the patient about all other therapeutic options and their consequences and will stress that a patient is able to rescind a request at any time and in any manner.

As family physicians, we must also offer the patient time to discuss complex concerns about their medical condition. This process includes determining with the patient and their loved ones what values, hopes, and fears lie behind the request. These might not always be the same as the patient's stated reasons.

For this process to be meaningful, the physician needs to know his or her patient well and needs to engage in attentive non-judgmental listening. Family physicians know that they should not take over the decision-making of competent patients, nor should they project or impose their own values on their patients. They must always avoid allowing their own perceptions to prejudge the quality of their patients' lives.

● (1220)

Family doctors need to be attentive to signs of not only biological or psychological distress but also of existential suffering. These often arise when individuals face declining health, diminished function, or the reality of impending death. Because patients might not always be aware of or be able to articulate their thoughts regarding these struggles, physicians have to be adept at discussing feelings and interpreting behaviours, and they have to be able to draw on the expertise of others to do so. The physician's attentive and empathetic listening, availability to discuss issues of concern, offer of appropriate supports, and expression of commitment to continuing care throughout the patient's illness are in themselves important therapeutic responses for patients and their loved ones.

We recognize that no other group of practitioners in the Canadian health care system is better placed and better equipped to take on this important and difficult role with Canadians than family physicians working in communities, large and small, across our country. The college intends to leverage the knowledge of its members and experts in the area to develop appropriate education resources and ensure that appropriate guidance is available to our members.

A physician who refuses to fulfill a patient's request for physician-assisted death for reasons of conscience still holds some responsibilities to the patient. As the primary providers of care, family doctors can assist their patients in finding a willing physician. This can be done through directly referring the patient to a willing physician, providing their patient with advice on how to access a separate referral service, or notifying the medical administrator at an institution, who would arrange for another referral.

A central information system for patients would support this process and help a great deal to avoid feelings of abandonment and confusion. It would also improve the standardization of information available across Canada on this important issue. The objecting family physicians will provide continuity of care and transfer the patient's medical record promptly and effectively if requested. Above all, the CFPC opposes any action that would abandon a patient without any options or direction.

The college believes that Canadians should have access to quality palliative care in their communities. Permitting physician-assisted dying should not be considered a substitute for efforts to improve comprehensive medical, mental health, and palliative care. Rather, these efforts should be intensified.

Individual physicians and the medical profession should recognize and act to support patients who have serious illnesses or disabilities and those who are dying. Physicians need to consider the patient's assessment of the overall balance of benefits and burdens of life-sustaining interventions for himself or herself. They also need to be able to maintain continuity of care when referring patients to the appropriate specialized care, provide coordination of care among different parts of the health care system, and ensure that patients are cared for by physicians and a team of health care providers whom they trust and who know them well.

As with any medical changes that arise in the legal context, ethical issues will need to be deliberated within medical colleges and by individual physicians. We maintain that family physicians should, above all, remain committed to their relationships with their patients and their patients' loved ones during this last chapter of life. Recognizing that those who have serious illnesses or disabilities and those who are dying are among their most vulnerable patients, family doctors are expected to be health advocates on behalf of such patients.

We believe that in order to be able to provide consistent and compassionate care for patients in this exceptional context, Canadian family physicians need to have a simple and achievable expectation of the legal and licensing entities that touch this aspect of their practice. They need clarity and consistency in the standards and requirements that govern what they can and cannot do and how their discussions and decisions with patients need to be documented.

● (1225)

We recognize the complexity of the issue and the concerns it will raise among some of our members. Poll after poll, however, confirms that this is a service that the people of Canada find necessary, and we will work with the physicians willing to provide this service to deliver it in a compassionate, ethical, and professional manner.

I want to thank you once again for the opportunity to present a family medicine perspective on this issue. We look forward to the legislative framework that will emerge and we are ready to continue the collaboration and discussion in this important area.

Thank you.

**The Joint Chair (Mr. Robert Oliphant):** Thank you, Dr. Lemire.

We'll continue with the Alzheimer Society. Ms. Lowi-Young will begin.

**Mrs. Mimi Lowi-Young (Chief Executive Officer, Alzheimer Society of Canada):** Thank you very much.

I would like to introduce Debbie Benczkowski, who is with me. She's the chief operating officer of the Alzheimer Society of Canada.

Good afternoon, joint chairs Senator Ogilvie and member of Parliament Oliphant, and to all the members of this special joint committee. Thank you for the invitation to appear this afternoon before this committee as it prepares to make recommendations on the framework of a federal response to physician-assisted dying.

Let me begin by saying that the Alzheimer Society acknowledges the necessity of the pending legalization of physician-assisted dying. The legislation that you will develop will shape end-of-life rights for many years to come.

The significant outcome of the Supreme Court decision of February 6, 2015, is that physician-assisted dying will no longer be considered murder under the Criminal Code of Canada. For people living with dementia and those who care for them, the related issues are both practical and ethical in nature.

This is a complex issue. The Alzheimer Society believes that Canadians living with dementia, and their families, should have the right to access palliative care and services and to have realistic choices on where and how they wish to live and die.

To begin, consent-to-treatment legislation is solely within the jurisdiction of provincial legislatures. In Ontario, for example, the Health Care Consent Act has been in place since 1996. It provides safeguards for people who are capable, or incapable, with respect to decisions for treatment.

Because of the progressive and ultimately fatal nature of Alzheimer's disease and other forms of dementia, this disease has become a special focus in the debate about physician-assisted dying. Alzheimer's is a progressive degenerative disorder that affects the brain. More than 747,000 people in Canada live with Alzheimer's disease and other forms of dementia. That number is expected to double to 1.4 million in the next 15 years. This is a growing public health concern. Recently the WHO, the World Health Organization, stated that dementia must be treated as a global health priority.

Given the nature of the disease, a person's ability to communicate needs and preferences diminishes over time. For those who care for them, it is difficult or impossible to know what the person with dementia comes to value over time, especially if those values are at odds with previously expressed desires.

Progression over time will vary from person to person. No matter the stage of the disease, people with dementia remain unique. They are whole people. Their rights and their needs must be recognized and respected.

Living with dementia brings enormous challenges, making end-of-life issues complex and personal. People with dementia deserve access to the highest possible quality of support and care throughout their lives. This reality contributes to concerns that a person with dementia will be vulnerable at the end of life, and at risk for untoward pain and treatment.

A diagnosis of dementia does not render someone immediately incapable, but anyone who has received the diagnosis will need considerable information and support in order to make an advance care directive. This is why end-of-life planning and care are so critical. The Alzheimer Society promotes early diagnosis so that people can make their wishes known and plan with their families for their future care.

With accessible, high-quality palliative care, Canadians with dementia may feel more confident about facing the end of their lives. Therefore, I'd like to stress three points.

First, people are not able to predict the exact nature of the progression of their own disease.

Second, people's wishes may change significantly over the course of the disease, which can last up to 10 years and more.

● (1230)

Third, and crucially, at the end of their lives, people with dementia would not be considered competent under the law to make a decision to end their lives.

In light of these points and with respect to physician-assisted dying specifically, the Alzheimer Society agrees with the view that doctor-assisted dying should only be considered under conditions when the person is deemed competent at a given point in time. If the person is not deemed competent, then the risks of abuse are simply too great.

It's conceivable that some people with early dementia, perceiving difficulty with family or friends, may make an early decision to request doctor-assisted death. This might take the form of a formal advance care directive provided to the next of kin. However, given the high degree of variation in the evolution of each person's potential path with dementia and also the possibility that their values and beliefs may change over time, we recommend that advance care directives for physician-assisted death should not have standing when the person lacks competence at the time of the potential health care provider intervention. The risks are just too great.

Today only 16% to 30% of Canadians who die have access to or receive specialist hospice palliative care and end-of-life care services, and this access depends on where they live in Canada.

To be clear, the Alzheimer Society believes that Canadians living with dementia and their families should have the right to access palliative care and hospice service and to have choices on where and how they wish to spend the latter parts of their lives if they live with dementia.

For these reasons, the Alzheimer Society advocates for a national dementia strategy, a pan-Canadian, collaborative partnership of experts to support quality care nationwide to provide governments, NGOs, and individual Canadians with the evidence-based information and tools they need to make informed decisions about living with dementia. A national dementia strategy will ensure that all Canadians with dementia, regardless of where they live, will have access to the same level of quality of care and services. To achieve this strategy, the Alzheimer Society has proposed the creation of the Canadian Alzheimer's disease and dementia partnership. The Alzheimer Society of Canada is looking to the federal government to fund this partnership.

Life does not end when Alzheimer's begins. The right to wellness must be protected, and stigma must be mitigated. The stigma associated with this disease can be as devastating as the changes that will occur in someone's life. Often it prevents people from even seeking a diagnosis and is a barrier for health care providers who must make it.

The Alzheimer Society launched the #StillHere campaign at the beginning of January for Alzheimer Awareness Month. The society is challenging Canadians today to recognize the people who are living with dementia in their communities and to think about ways to help them live better lives.

Let me conclude by reiterating the views of the Alzheimer Society on the topic at hand, physician-assisted dying.

Regardless of where legislation leads, the Alzheimer Society emphasizes that improving access to quality palliative care for all Canadians and their families facing life-threatening diseases, including dementia, must remain a public health priority. Federal legislation should enable the provinces to determine within each jurisdiction how provisions for advance care planning by people with dementia will be accommodated.

● (1235)

A national dementia strategy will help realize this goal for people living with dementia. It is an essential step in managing the dementia crisis for Canadians today and for changes that the journey might bring to Canadians' views and practices in the future related to individual autonomy and empowerment at the end of life.

Thank you very much.

**The Joint Chair (Mr. Robert Oliphant):** Mr. Lemieux.

[*Translation*]

**Mr. Denis Lemieux (Chicoutimi—Le Fjord, Lib.):** Thank you, Mr. Chair.

My question is for Ms. Lowi-Young, from the Alzheimer Society of Canada.

In your presentation, you talked a lot about advance consent.

When someone who is still competent under the law wants to write an advance directive, how can we refuse them a physician-assisted death?

[*English*]

**Mrs. Mimi Lowi-Young:** I think we're saying that this issue is a very complex one. It's important to express one's values and beliefs to family members at a time when one can. I think we're saying that physician-assisted dying is a very difficult issue in terms of context and the timing of such consent being given.

● (1240)

[*Translation*]

**Mr. Denis Lemieux:** I have no further questions, Mr. Chair.

[*English*]

**The Joint Chair (Mr. Robert Oliphant):** Would you like to give the floor to one of your colleagues?

Go ahead, Madame Shanahan.

**Mrs. Brenda Shanahan (Châteauguay—Lacolle, Lib.):** Thank you very much. My question is for Madame Lemire.

You spoke very eloquently about the role of the family physician in assisting patients with end-of-life options. We heard testimony earlier from Mr. Jay Cameron from the justice centre, who said that these decisions should be referred to a superior court judge.

What is your reaction?

**Dr. Francine Lemire:** It is one of concern, in terms of where a request of this nature would fit in the context of the continuum of care that exists in a family physician-patient relationship. We would have concerns with that. We would prefer to see this as a medical act that is part of tons of other medical acts that physicians are involved in and are considering with their patients.

Obviously, there would need to be the appropriate consultations, documentation, and all of that, but we would view this with concern.

[*Translation*]

**Mrs. Brenda Shanahan:** I have another question.

We are currently going through this in Quebec. Can you tell us a bit about the experience of Quebec family physicians in this area?

**Dr. Francine Lemire:** I cannot make specific comments because I have not spoken to any family physicians who have been involved in the process. However, we do know that, since December, assisted suicide has been used in some cases.

Over the next few months, we intend to carry out a somewhat more appropriate consultation through the Quebec College of Family Physicians to better understand how things are going.

Generally speaking, we are impressed by the process currently in place in Quebec. Through the Collège des médecins du Québec—Quebec college of physicians—physicians will have to be prepared to incorporate the procedure into their scope of practice.

**Mrs. Brenda Shanahan:** I would like to ask one last question. Is palliative care part of that range of available services?

**Dr. Francine Lemire:** There is no doubt that palliative care is very important and that what is currently being done in Canada in that area must be improved. However, I believe that Canadians have been very clear. Although quality palliative care is provided in Canada, Canadians want a separate right to have access to that service, where assisted suicide would be considered.

We have to remember that most palliative care in Canada is currently being provided by family physicians, that they are the ones incorporating that care into a complete and comprehensive scope of practice and the ones who have additional qualifications in palliative care. Those physicians are telling us that they do not want to see assisted suicide as the end of what is happening in palliative care. They really want to be able to keep things separate.

[*English*]

**The Joint Chair (Mr. Robert Oliphant):** *Merci.*

Mr. Albrecht.

**Mr. Harold Albrecht (Kitchener—Conestoga, CPC):** Thank you, Mr. Chair.

Thank you to all of our witnesses for being here today.

Many times we hear the criticism of the medical profession that they are too focused on the medicalization of dying, and I found your presentation to be refreshingly different from that. You're addressing what I believe are many of the ethical and moral issues that underlie this big question we are facing as parliamentarians, which is what does it mean to be human, and what gives human life meaning?

I was especially pleased to see these kinds of thoughts coming from those who are charged with the responsibility of licensing our physicians and surgeons. It is really encouraging for me.

I want to read into the record some of the statements you made in your paper, because I think it is crucial for all Canadians to hear this, and, unfortunately, they won't all be able to read your paper.

> The term *dignity* can have different meanings and is open to interpretation.....
>
> There is a general agreement that dignity is intrinsic in all human beings because all have equal worth and belong to the human community. Dignity in this sense cannot be diminished or lost by such changes as disfigurement, illness, or decline in capacities.
>
> There is another sense of dignity that is related to the flourishing or well-being that patients experience in their lives. Dignity as associated with flourishing and well-being can be subject to variation with illness and disability for some individuals, particularly for those who are concerned with their loss of control or independence. These concerns in many patients can be mitigated and addressed by effective care, so that their dignity in this sense can be preserved or even enhanced. In other patients, their adjustment to and acceptance of the limitations imposed by illness, disability, and death can result in overall well-being and the patient and can provide a sense of meaning and inspire their loved ones and others in the midst of suffering.
>
> A third sense of dignity, *attributed dignity*, is connected with how patients perceive themselves or how they perceive others' regard for them. Negative self-perception and concerns about being a burden to others can often lead patients to consider physician-assisted suicide and euthanasia.

In another paragraph, you indicate that one of our challenges is in challenging attitudes and behaviours that regard some patients as non-productive and costly members of society—for instance, referring to the demographic of aging Canadians as the "silver tsunami". These attitudes and behaviours among care providers can reinforce patients' sense of being a burden to others and their perception that they have a duty to die.

One of the foundational concerns I have, as a member of Parliament charged with the responsibility of making recommendations to the government as to how we craft legislation, is how we can be 100% certain that what today could be a right to die could, through some kind of coercion, moral or otherwise, become the duty to die. How can we be 100% sure? What kind of safeguards can we put into our recommendations to the government that we will do all we can to be sure that does not happen?

● (1245)

**Dr. Francine Lemire:** You expect an answer from a family doctor in a minute or less.

Some of the segments of the paper produced by the college that speak to dignity have also been covered by my colleagues from the Alzheimer Society in terms of the slippery slope that we are on, and yet, at the same time, we need to stand up and be counted and listen to what Canadians have told us.

I don't have magic recommendations other than to suggest that there ought to be clarity around the process and clarity around what is expected of physicians. I've already expressed my concerns around referral to a court. I would suggest that the concept of consultation by two physicians is important. The process of a request that is first expressed but must be expressed verbally within a certain period of time is also important in making sure a rash decision is not being made. During the time between the first request and the second request, including what happens before, really good consideration between the team that is looking after that patient and the patient himself or herself needs to take place to make sure there is good consideration of the options and everything that is described in the paper and of what I've said. However, once that second verbal request is made and a written request follows, we must ensure that not too much time elapses between meeting the request and providing the required care in a caring and compassionate manner.

I think clarity around what is expected of the profession, clarity of the documentation, and safeguards around the process so that there are two requests, including one verbal one, are all important.

● (1250)

**The Joint Chair (Mr. Robert Oliphant):** Thank you, Dr. Lemire.

Mr. Rankin.

**Mr. Murray Rankin:** Thank you, Chair. I'll be sharing my time, please, with Madame Sansoucy.

I would like to first ask Ms. Lowi-Young of the Alzheimer Society for clarification. I just want to make sure I've grasped the perspective.

I believe your position as an organization is that there should not be advance directives for Alzheimer's patients because the risks are too large. I'm wondering if you were here this morning when we had testimony from the Dying With Dignity people. They mentioned Gillian Bennett, whose blog, deadatnoon.com, talked about her difficult choice in this area when she had advanced dementia. They also made reference to a nurse, Ms. Bentley, who made it clear that she did not want to be in this situation. She had stage seven dementia and was still being spoon-fed, contrary to her wishes and the wishes of her family.

Those are examples, I think, on the other side of this issue. I just want to make crystal clear whether or not your view is that it ought not to be allowed to Ms. Bennett or Ms. Bentley.

**Mrs. Mimi Lowi-Young:** No, we do believe that the advance directive is appropriate for the substitute decision-maker. I think what we're saying is that with dementia it's very complex, only because the disease happens and progresses over a long period of time, and the context may be different during the various stages of the progression of the disease.

I think I want to clarify that. I mean that there needs to be a substitute decision-maker. That's what we were saying.

**Mr. Murray Rankin:** That's very helpful. Thank you. I just wanted to clarify that.

Dr. Lemire, I would like your comments on whether there should be two physicians to confirm the consent or whether just one is sufficient in the family doctor context. Is one likely to be adequate, or would you suggest the need to have two, as other witnesses have sought?

**Dr. Francine Lemire:** We support having two physicians, with the most responsible provider being that first person who can view the request in the larger context as described, and then a second consultation by another physician.

**Mr. Murray Rankin:** Should it be a specialist, or is that not material?

**Dr. Francine Lemire:** I personally would not feel that it necessarily needs to be a specialist. Perhaps only in instances where there may be questions with regard to the competence or capacity of the individual would there be a need for more specific, specialized expertise.

**Mr. Murray Rankin:** Thank you.

[*Translation*]

**Ms. Brigitte Sansoucy:** I want to thank the witnesses.

My question is for Dr. Lemire.

Some witnesses have said that only physicians could provide assistance to die to patients who request that assistance, as the Supreme Court of Canada decision in Carter talked about a physician's assistance to that end. That is even more true in the English version.

However, the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying says that members of regulated health professions—including registered nurses and physician assistants—should be able to provide assistance to die under the guidance of a physician or a nurse practitioner.

According to your organization, which health care professionals should be allowed to provide assistance to die to patients who make the request, especially those who live in remote areas or in the north and have more restrictive access to a physician?

**Dr. Francine Lemire:** We really believe that physician-assisted dying is the responsibility of family physicians. That said, I would not say that it is exclusively their responsibility. For instance, nurse practitioners who are working in more rural or remote regions should also be authorized to provide that assistance, especially if their professional body is prepared to include the process in their scope of practice.

For an informed decision to be made, I think that a consultation with a family physician, based on a consensus process the patient is involved in, is completely appropriate.

● (1255)

**Ms. Brigitte Sansoucy:** We have also been told about telehealth practices that could foster collaboration between physicians who are not on site and nurses, for instance.

**Dr. Francine Lemire:** We support that tool as a consultation vehicle that is part of this important decision.

**Ms. Brigitte Sansoucy:** Thank you.

[*English*]

**The Joint Chair (Mr. Robert Oliphant):** *Merci.*

I've asked if Senator Seidman would share six minutes with Senator Joyal so that they can each have three minutes and we can get both of them in and still end at 1 p.m.

Thank you very much.

**Hon. Serge Joyal (Senator, Quebec (Kennebec), Lib.):** To show you how amenable we are, I will say yes.

**Hon. Judith G. Seidman:** Thank you.

Dr. Lemire, you stated that physician-assisted dying is not just about process and procedures but very much about the relationship between the physician and the patient. Clearly we need to deal with clarity for professionals, as you yourself put forward as well.

My question to you is this: should the process involved in making a request for physician-assisted dying and the process involved in providing physician-assisted dying be established through federal legislation?

**Dr. Francine Lemire:** We are on the record as saying yes, and I still believe this is important. That really is around equity. I believe that a federal process would strengthen equity for Canadians around this issue.

**Hon. Judith G. Seidman:** It's true that the provincial regulatory medical authorities have established guidelines for their members in relation to physician-assisted dying. Do those guidelines provide somewhat of a satisfactory framework?

**Dr. Francine Lemire:** The guidelines that are probably best known, as we referred to earlier, are the ones that exist in Quebec. I would say, based on everything that I've heard from my colleagues in Quebec, there is a sense that they are appropriately framed.

Guidelines are emerging as they are issued by the licensing authorities in other provinces. I must admit that I've not had the opportunity to study those in as much detail as I have in looking at the Quebec situation.

**Hon. Judith G. Seidman:** Shall I defer the rest of my time now?

**The Joint Chair (Mr. Robert Oliphant):** It would be good if you wanted to. You have 45 seconds, or you can pass.

**Hon. Judith G. Seidman:** I'll defer to Senator Joyal.

[*Translation*]

**The Joint Chair (Mr. Robert Oliphant):** Senator Joyal, go ahead.

[*English*]

**Hon. Serge Joyal:** Thank you, Senator.

Madame Lowi-Young, I would like to come back to your statement or answer to our colleague Mr. Rankin.

If I understand the position of the Alzheimer Society, you're not opposed in principle to advance consent, but you advise us that there are three points we should keep in mind, especially the timing of when the consent is being given and appraised during the life of a patient. Am I right in understanding your position the way I have stated?

**Mrs. Mimi Lowi-Young:** Yes, that is correct. If you look at Alzheimer's disease and dementia, the progress of the disease can happen over a long period of time. It can be 10 years or more. It's that there is usually a substitute decision-maker who has to understand the values and the beliefs and the philosophy of the individual or family member they are caring for.

We are saying that advance planning, once somebody is diagnosed, needs to be considered in the knowledge that the whole issue of physician-assisted dying is a complex one, because he context in which the decision gets made changes over time, from the initial diagnosis until when the person is near the end of life.

We're saying that fundamentally their access to care should be to high-quality palliative and hospice care. That's very important, because the issue of how to determine what the person's wishes are at the end of life is very difficult, since they cannot state clearly what their wishes are.

**Hon. Serge Joyal:** In other words—

**Mrs. Mimi Lowi-Young:** We're just saying that because of the needs this group of individuals has and because of the nature of dementia and Alzheimer's, all these issues need to be considered in the work you're doing in creating the framework for the legislation.

● (1300)

**Hon. Serge Joyal:** Thank you.

[*Translation*]

Dr. Lemire, if I may, I will come back to page 4 of the brief your association sent us on January 18. I received a letter, and I assume my colleagues received one, as well. The brief was produced by the College of Family Physicians of Canada. On page 4, the document talks about a physician's right to freedom of conscience. Here is what is stated in the second paragraph. Do you have the document with you?

**Dr. Francine Lemire:** I don't, but go ahead.

**Hon. Serge Joyal:** If it's okay with you, I will read the following in English, since the document I received was in English.

[*English*]

It concludes:

> ...physicians must be cognizant of the scope of their responsibility in providing care to a patient. The CFPC opposes in principle any action that would abandon a patient, without any options or direction.

That's under the heading "What is the meaning of a physician's right to freedom of conscience?"

Could you expand on that sentence, where you say that your association "opposes in principle any action that would abandon a patient without any options or direction", in view of a physician refusing to assist a person in dying?

**The Joint Chair (Mr. Robert Oliphant):** You have 30 seconds, please.

**Dr. Francine Lemire:** We believe physicians have a responsibility not to abandon. If a physician finds himself or herself in a position of not being able to conclude the process, that physician can still do the exploration that is discussed in this document. If the wish of the patient is still to proceed, then the physician ought to either refer to another physician or provide sources of referral that the patient can access in such a way that the patient is not left having to fend for himself or herself at this important time of life.

There's a responsibility for the physician, even though the physician may not be performing the procedure, to attend to other medical needs, to transfer records, to connect with loved ones in a process that not only encompasses the end of the life of that patient but that also goes beyond. Very often, as family physicians, we have awareness of the spouse, of the children, of the family.

**The Joint Chair (Mr. Robert Oliphant):** Thank you, Dr. Lemire.

This concludes our meeting. We will meet again in this room at 4:30 this afternoon.

We are adjourned.

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