

Special Joint Committee on Physician-Assisted Dying

Thursday, January 28, 2016

• (1730)

[English]

The Joint Chair (Hon. Kelvin Kenneth Ogilvie (Senator, Nova Scotia (Annapolis Valley - Hants), C)): Colleagues, we have a quorum. I'm calling the meeting to order.

[Translation]

I want to welcome you to the seventh meeting of the Special Joint Committee on Physician-Assisted dying.

[English]

I'm Kelvin Ogilvie, a senator for Nova Scotia, co-chair of the committee along with my colleague Mr. Robert Oliphant, member of Parliament for Don Valley West.

Welcome to this evening's meeting. In the first hour, we have three witness groups. Appearing as an individual is the Honourable Steven Fletcher. Appearing by video conference from Winnipeg, Manitoba, are Mr. Dean Richert and Ms. Rhonda Wiebe, from the Council of Canadians with Disabilities. Also appearing by video conference, from Waterloo, Ontario, from Dying With Dignity Canada, is Ms. Linda Jarrett, who is a member of the disability advisory council.

Welcome to all of you.

I remind you that you have approximately 10 minutes for your presentations. The council will share their total time. I will also remind everybody that the witnesses, our panel members, have a total of five minutes for the question and the answer to the question.

In Senate meetings, I always call for the video conferences first in case there are electronic glitches that occur, and since we're all electronified while here, I'm going to start with the video conference.

I would invite Ms. Jarrett to present first.

Ms. Linda Jarrett (Member, Disability Advisory Council, Dying With Dignity Canada): First of all, I would like to thank you for the opportunity to appear before this council. I do appreciate the fact that I can speak.

My name is Linda Jarrett. I am 67 years old. I am a wife, mother, grandmother, mother-in-law obviously, and 17 years ago I was diagnosed with secondary progressive multiple sclerosis. At the time, I truly felt blessed, in a way, that I was diagnosed at such a late age of 50. Unlike so many people diagnosed with MS in their early 20s and 30s, I have had a chance to live a very active life. I've had a wonderful career as a teacher and have been able to actively take part in the raising of our two children.

I am blessed in that way, but I am also cursed in that multiple sclerosis is a very insidious disease. In my case, with secondary progressive MS, there has been no cause found for MS, and a cure certainly has not been indicated in the foreseeable future, especially for somebody with my version of MS.

As a result of that diagnosis 17 years ago, in the last five or six years I started thinking about what my life was going to be like. I personally do not want to spend the final years of my life in a longterm care facility, no matter how lovely such a place might be, being taken care of 24-7. That's when I started looking into what my options could be.

Now, back six or seven years ago, the options were that I could hasten my own death while I was still physically capable of doing so, and not implicating any members of my family or friends. With the introduction of the concept of physician-assisted dying, and with that incredible announcement last February, I suddenly realized that I could still love the life I have, knowing that there could be a solution to avoid the end of life I don't want.

In any case, that's just a little bit of background as to where I am now, today, presenting to you as a member of the disability advisory council to Dying With Dignity Canada. We are a group of individuals with disabilities that compromise our ability to take part in the normal routines of daily life. Members of our disability advisory council include social activist Margaret Birrell; a former palliative care and public health doctor, Dr. Greg Robinson; and a former president of the Canadian National Institute for the Blind, Jim Sanders.

In 2014, Dying With Dignity Canada commissioned an Ipsos Reid poll that included a statistically significant sample of people with disabilities. These people were those who answered the following question: Are you permanently or severely disabled such that you cannot take part in the basic activities of daily living without assistance?

An amazing 84% of those people with disabilities answered this question: As long as there are strong safeguards in place, how much do you agree or disagree that a doctor should be able to help someone end their life if the person is a competent adult who is terminally ill, suffering unbearably and repeatedly asks for assistance to die?

• (1735)

I can't emphasize enough that it was 84% of the disabled participants in that survey that agreed or strongly agreed with the right to physician-assisted dying. That poll was valid plus or minus 11.5%. Another poll done in the U.K. by YouGov had a significantly larger range of individuals with disabilities being polled, and 79% of those with disabilities support or strongly support the right to physician-assisted dying. They answered this question positively: "Whether or not you would want the choice for yourself, to what extent do you support or oppose the legislation of assisted dying for adults of sound mind with a terminal illness?"

Our disability advisory council helped to inform and supports the seven principles for legislation outlined by Dying With Dignity Canada, and I do hope that handout was provided to you ahead of time. I am going to refer to a couple of points on it, but the handouts, which were sent ahead of today's meeting, you can certainly refer to later.

I'd like to flag the second principle, which concerns "advance consent". The members of our council believe that as with other major life-ending decisions, we should have the ability to make our decisions known now when we are competent and hopefully have them carried out later when possibly we will not be. I myself have a "do not resuscitate" order in place because I know full well that I do not wish to be resuscitated should some life-ending event happen to me. What if I were to have a stroke and be completely paralysed and unable to communicate? In that situation, I know that I would want assistance to die, and I believe I should be able to make that request now while I'm competent and have it carried out later when perhaps I will not be.

To ensure that physician-assisted dying is provided only to patients who truly want it, we support additional procedures that are not currently part of end-of-life medical care. We do this with caution, knowing that any additional procedures can also sometimes become a barrier to access. For example, the two procedures that we endorse are that two physicians verify that there has been free and informed consent for physician-assisted dying and that every case be reviewed after the patient has died and aggregate data be compiled and made available to the public.

As individuals who happen to live with disabilities, we are aware that resources and support are sometimes lacking, and accordingly in our fleshed-out policy on physician-assisted dying, we include a statement noting that all people, including those with disabilities, should have the support and resources necessary to live their life to its fullest capacity.

We accept that a person can be situationally vulnerable because of factors that do not directly relate to their disabilities or to their disease. Factors such as isolation and financial distress are sometimes more likely to be encountered by people with disabilities. Accordingly we believe that physicians should be trained to assess situational vulnerabilities not just for physician-assisted dying but for all end-of-life decisions.

• (1740)

The members of our disability advisory council strongly feel that the law needs to strike a balance to protect vulnerable people from having an assisted death they don't really want and, from my point of view and our council's point of view, to ensure access to assisted death for those who do have an enduring wish for it.

To this end, we propose two further key principles. The first is that doctors, while having the right not to administer or prescribe lifeending medication, must be willing to provide information and transfer the care of patients who seek an assisted death, so that patients are not abandoned. We don't want someone who is desperately ill, with great pain, being given a website or a phone number or the Yellow Pages and being told to find another doctor.

We further believe that tax-funded institutions, whether they be hospitals, hospices, or long-term care facilities, must provide assisted dying on their premises to patients who request it. For example, some of our members in British Columbia are concerned that they may need emergency medical care and perhaps will be transferred to one of the Catholic hospitals in that province. They don't want to give up their right to an assisted death just because the hospital they have been transferred to has a historical association with a particular religious viewpoint on assisted dying.

It is notable that some of the most prominent proponents of physician-assisted dying are the disabled: Kay Carter, Sue Rodriguez, Gloria Taylor, and Joe Arvay, the lead counsel for the plaintiffs before the Supreme Court just over a year ago, who gave us the right—possibly—to physician-assisted dying. He did this from his wheelchair.

Our diseases and disabilities have robbed us of much, and I ask you, do not add to this burden by compromising our choices and our autonomy. I will repeat again that 85% of people with disabilities said, in a valid, accepted poll, that they would strongly support the idea of physician-assisted dying.

Please do not allow us to be represented as opposing this compassionate and humane choice. Again, I emphasize that it is a choice. No one is asking to be put to death against their will, but please allow those of us in the disabled community the right to access our choice for physician-assisted dying.

Thank you so much for listening to my babbling.

• (1745)

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you, Ms. Jarrett.

I'm now going to turn to the Council of Canadians with Disabilities.

You are on the air.

Ms. Rhonda Wiebe (Co-Chair, Ending of Life Ethics Committee, Council of Canadians with Disabilities): Thank you, Mr. Chair and committee members.

My name is Rhonda Wiebe, and I am here with Dean Richert. We are the co-chairs of the ending of life ethics committee for the Council of Canadians with Disabilities.

The Council of Canadians with Disabilities, or CCD, is a national human rights organization of people with disabilities who are working for an inclusive and accessible Canada. The CCD has deep roots in advocating for equality, human rights, citizenship, selfrepresentation, partnership, and barrier removal. Its rich history includes its representation of the concerns of Canadians with disabilities in the Supreme Court of Canada and working to ensure equal rights in access to education, transportation, and other issues, including the one that is before us today.

Within the CCD structure, the ending of life ethics committee seeks to focus attention on and prevent private and societal actions that make people with disabilities die prematurely due to inequalities in health care, societal neglect, social prejudices rooted in fear, and negative perceptions about life with a disability.

I have worked for over two decades as a disability rights advocate at the local, provincial, national, and international levels. I also spent five years as a researcher examining end-of-life issues at the faculty of medicine at the University of Manitoba, but most importantly, I am also someone who has the direct experience of living with a lifelimiting and sometimes fatal medical condition that affects almost all my vital organs and has left me with considerable vision loss and some mobility issues.

The CCD knows that adjusting to living with disability is hard. I have had 20 surgeries. Each time I undergo one, I have doubts about whether I will benefit or lose capacity. When I do lose capacity to see, to move, to dress myself, to walk, and to work, I have to adjust not only the perception others have of me but also my perception of myself. Although my experience is personal, it is also typical of those the CCD represents. It is something that people with disabilities have in common.

A few years back, I facilitated a support group for young people who suddenly acquired disability through accidents or onset of disease. In the first two years after that happened to them, each one of them experienced moments of suicidal ideation. Every person living with disability knows these dark places.

We are encouraged to hear that Wanda Morris, of Dying With Dignity, has acknowledged that her organization will not assist those who have recently acquired a disability to seek death. We know that with the right supports we can go on to have lives that, although they are different from what we once thought they would be, are nevertheless full lives. Steven Fletcher, former MP from Manitoba, also has acknowledged that if he had had this option, he might have ended his life shortly after his accident. It took him several years to find a new vision for himself, one that included being a parliamentarian.

These common experiences have led the CCD to carefully consider our response to the recent Supreme Court of Canada decision to allow physician-assisted dying. We come to you today asking you to consider three points as you begin the process of laying out a framework. All our points grow not only from our expertise as an organization but also from the Supreme Court's concern that protection of the vulnerable is a priority. The court determined that a safeguard system that imposed "stringent limits that are scrupulously monitored and enforced" would achieve a balance that would both enable access by patients to physicianassisted dying and protect those who are vulnerable and may be induced to commit suicide.

Vulnerability and suffering often go hand in hand. A review of clinical research on suicide prevention and vulnerability within the health care context indicates a wide range of factors associated with suffering that can lead to suicidal ideation and the request for physician-assisted dying. In our brief, we've listed factors that increase the risk of suicidal ideation, as put together by the American Psychiatric Association. We won't go into them now.

• (1750)

The three points we want to bring forward for your consideration are born out of our concerns regarding vulnerability.

Mr. Dean Richert (Co-Chair, Ending of Life Ethics Committee, Council of Canadians with Disabilities): First, CCD is requesting that a vulnerability assessment be mandated in order to ensure that a person requesting physician-assisted dying meets the criteria of that request. In Carter, the court acknowledged that any set of safeguards must recognize the complex and sometimes subtle and subconscious factors related to a request for physician-assisted dying. This confirms, for us, the requirement for a vulnerability, informed consent, and capacity assessment process. Not being vulnerable to inducement is a criterion.

With respect to informed consent, it demands that individuals requesting physician-assisted dying must have information regarding the supports in the community that deal with issues related to poverty, isolation, discrimination, and devaluation. Our question is whether or not a family physician can provide all of this information. It may require someone more qualified to inform the individual of these supports. For CCD, providing such information is highly relevant in determining whether a person may be vulnerable to inducement.

As stated before, it is our understanding that Dying With Dignity has indicated that they agree with CCD that persons newly diagnosed with a disability are vulnerable, and should not be permitted to have assisted dying performed. It is also our understanding, and important to note, that two national polls, one from the Canadian Association of Retired Persons, just recently put out, and the other from the external panel, when they dealt with the issue of physician-assisted dying, indicated that a majority of Canadians do not support physician-assisted dying without a prior review. With respect to people with mental health issues, very few Canadians believe physician-assisted death is a solution.

Secondly, we recommend a prior review board process. The paperwork that is necessary—for example, the vulnerability assessment, capacity and competency, along with the assessments of two physicians—would be submitted with the application by a patient requesting physician-assisted dying to a review board. A review board or a review panel, not a physician, would make the ultimate determination on whether a request for physician-assisted dying will be given. We submit that the review panel should be chaired by a federally appointed judge to ensure consistency in reasons for judgments and facilitate Canada-wide standards. This is important. This is a Canada-wide standard. It should not be left up to individual doctors, nor individual provinces, to determine what the criteria are that have been articulated by the Supreme Court of Canada.

• (1755)

Ms. Rhonda Wiebe: Finally, CCD puts forth the need to establish means by which all Canadians who need it will be provided with adequate palliative care.

Canada now finds itself in the bizarre situation where we have the right as citizens to ask a physician to help us end our lives, but we don't have the legal impetus for the right to palliative care. It is not covered under the Canada Health Act, and it is acknowledged to be available to only a minority of Canadians who require it. It is unconscionable that people should choose to die through physicianassisted dying because they have no choice, due to a lack of palliative care.

Yes, palliative care will require a national political will, health care supports, and dollars, but let's not base our health care strategies on what's cheaper instead of on what is the right thing to do.

The Honourable Sharon Carstairs, in her 2010 Senate report "Raising the Bar: A Roadmap for the Future of Palliative Care in Canada", recommended the establishment of a Canada-wide strategy on palliative care as a partnership between the federal, provincial, and territorial governments and the community, which would pave the way for consistent minimum standards and benchmarks for nationally available palliative care services. She recommended the establishment of a Canadian palliative care capacity-building fund and also recommended that the provinces ensure that palliative care is covered under all provincial and territorial health insurance plans. CCD highly endorses Mrs. Carstairs' recommendations.

To sum up, CCD asserts that there are many social, economic, and other environmental factors that increase the vulnerability of persons with disabilities, especially the newly disabled. Careful scrutiny must take place to ensure that there aren't other remedies, besides death, that will lessen the suffering and indignity of these people.

Second, a review process that is easily accessible but does not necessarily require an oral hearing and is expedited quickly, as David Baker has articulated, say within 45 days from application to decision, is a safeguard that protects both doctors and patients.

Finally, CCD acknowledges that the crossover between the request for physician-assisted dying and the lack of access to palliative care is clear. There must be appropriate options so that real choices can be made available to all Canadians who want to have a good death.

Thank you.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you very much.

I'm now going to invite the Honourable Steven Fletcher to present.

Hon. Steven Fletcher (As an Individual): Thank you very much.

[Translation]

I am happy to be here this evening.

[English]

As many parliamentarians here, including the co-chair, will attest, none of us ever think we're going to be former parliamentarians—

Voices: Oh, oh!

Hon. Steven Fletcher: —but yet here we are, so I am very grateful to have the opportunity to speak in front of this group and give you my two cents on legislation that's really important. I'm going to go really fast, because there's a lot of ground to cover in a short time.

First, when I was 23, I had everything going for me. I had just graduated from engineering. I was driving to a gold mine in northerm Manitoba. I had a beautiful girlfriend. I was athletic. All that stuff was going well, and boom, I hit a moose with my car. The moose went through the windshield, the car went into the ditch, and it was a long time before I got to a hospital, as this was in 1996, before cellphones.

I was 23, and in an instant, I found myself completely paralyzed from the neck down. What does that mean? It means I cannot move below the neck. I do not feel a sense of touch, pain, or pleasure. I have no control of my bodily functions. I obviously have to rely on caregiving 24 hours a day, seven days a week, for the rest of my life.

I was told that if I were to survive, I would be in an institution. That's not what you want to hear. Mind you, after I was elected I did go back and say, "I don't think you meant the Parliament of Canada."

Voices: Oh, oh!

Hon. Steven Fletcher: I was completely paralyzed and intubated. This is very important. I had tubes in my nose going to my lungs, and because my lungs had essentially collapsed—I didn't have a diaphragm helping me breathe like everyone else—I was on a machine for about three months, fully conscious, but getting phlegm sucked out of my lungs minute after minute, hour after hour, day after day, week after week, month after month.

There is no pain medication that can deal with that. It is terrifying. It is impossible to sleep. You think you're going to go mad. You can't talk to anyone. You're experiencing massive amounts of pain, such that your head wants to explode, but you can't do a thing about it. I call it "well-intentioned torture". That's what they were doing.

When I was finally able to breathe and speak, two things happened. I had my family gather around. I told my mom and my dad—my dad is with me tonight—and my brother and sister that I loved them more than anything. Then I asked them to get my lawyer. I did not want to ever go through that again. The lawyer advised me that what I was asking was probably illegal, but I wanted it written down anyway, just in case. That was 20 years ago. Let's fast forward. Sue Rodriguez is an example of a person who all the resources in the world cannot help at the end. I know that. I had experienced that. I was going to get better, and I was 23. I didn't believe the doctor's prognosis anyway, until much later, but Sue Rodriguez was going to drown, hopeless, in pain and in terror. She was denied what everyone in this room would want: an end to the suffering.

• (1800)

I've long been an advocate of the empowerment of the individual, personal autonomy, and having the government stay out people's lives as much as possible. I've written extensively on this issue. I've written articles across this country. Even *The Economist* magazine has asked for submissions. In fact, I have a book here called *Master of My Fate*. I can't distribute it because it's not translated, but you will find it in your mailboxes. It goes through the whole political saga.

I will skip that other than to say that you will have in front of you three private members' bills, two that I introduced and one that Nancy Ruth and Larry Campbell introduced in the Senate. The first bill deals with amending the Criminal Code. It's about five pages, and it has some of the safeguards that you would like to consider, I think. The second bill includes a panel, or some sort of review board, to check for best practices. After five years, say, it would report to Parliament. It would collect empirical evidence to find out why people are making the requests and what we can do to empower people so that they choose life. But we also have to recognize that sometimes people will choose death. In fact the Hippocratic oath recognizes that, if you read it.

The response to the bills in Parliament was deafeningly quiet. Harold's laughing, because he knows that everyone was.... It wasn't a good place to be—except all the media, virtually across the country, left-wing and right-wing, accepted it; talk-show radio, TV shows. It turned out that over 80% of Canadians supported physician-assisted death, even in the disabled community. The response I received through email was overwhelming. I had thousands of emails from people telling me their most personal details.

Let's go to today. What is central in all of this is that the individual must be a Canadian or permanent resident, must be 18 or older, and must be cognitive. Don't make it complicated. That's it. Those are the criteria. All you have to do is cut and paste that part of the decision into the Criminal Code.

I agree completely with CCD that we should provide the resources, and increase the resources, so that people do choose life, but again, there are situations where all the resources in the world won't matter. I think that's why a lot of people in the disabled community at large do support physician-assisted death. But I would ask those in the disabled community with reservations about this to be more empathetic to the people who are suffering. Having someone suffer, starving themselves to death, or being in pain or in terrible suffering, down the hall or down the street at the seniors residence or in a hospital or at home, having them live in pain and terror—it doesn't make my life better as a Canadian with a disability. It just makes me sad.

• (1805)

You have to recognize that people suffer, and to impose our view or for any group to impose any view on anyone else is un-Canadian and, I would say, unconstitutional, because doing so infringes on freedom, liberty, and the ability for self-determination.

With regard to doctors, I've heard a lot of testimony from doctors on how this is going to be tough love.

To the doctors and the medical profession, I say be professional, be tough. It's not about you. It's not about the medical profession. It's about the individual and his or her choices. If the person is a cognitive adult, why on earth would we impose our views on what their quality of life is on them? I'm not talking about someone with a bad hair day. There is obviously going to have to be some reason, and common sense needs to be applied.

Having the committee bring forward legislation really makes me concerned, because anything that comes from Ottawa is bound to fail when it comes to the cross-jurisdictional issues of criminal law and health care. I would suggest that the committee stay as close to the Carter decision as possible and allow the provinces to determine their own fates. That is what's happening already with Quebec. In fact, Quebec has to go further. They have to amend the law to provide for more circumstances.

Last, on the issue of advance care directives, after this four-month period is up, I think there will be a paradigm shift in what is allowed in a living [*Technical difficulty—Editor*]. I think people need to be empowered to say that in 20 years from now if they have dementia or these things or they end up in a terrible car accident or whatever, and they so choose, then they would not want to live. I can go on. I'll give you the book.

Ladies and gentlemen, *Invictus*, the famous poem, says, "I am the master of my fate: I am the captain of my soul". Let's move forward with hope, compassion, empathy, and mercy.

• (1810)

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you very much.

Madam Shanahan.

Mrs. Brenda Shanahan (Châteauguay—Lacolle, Lib.): Thank you very much, Mr. Chairman.

I thank all the witnesses for their very moving testimony here this evening. It brings to mind the kinds of concepts we're talking about. Autonomy, competency, even the right of refusal are concepts that we in the abled community take for granted.

I address my question to the Hon. Mr. Fletcher.

I wonder if you can speak more on what those concepts are, what those words mean in the disabled community.

Hon. Steven Fletcher: The reason people have taken their lives before the time has come—people from Dying With Dignity named some high-profile cases—is that they are terrified about what might happen. If they lose the ability to travel to Switzerland or administer a fatal dose or whatever, they will be trapped in their bodies, miserable forever.

What the Supreme Court has said is "we hear that". They recognized that people are ending their lives early due to that, and that the law as it is was causing people to suffer. That was part of the testimony. The Government of Canada agreed to both those points.

What this legislation will do—or the lack of it, because you don't even need legislation, in my view—is provide comfort to people like Sue Rodriguez or like me when I was 23. What if I had been 53 or 73? See, things change. I would say that we need to be empathetic, not just as persons with disabilities looking out but obviously the other way. So much depends on where you are in your life, what your values are, what your religion is, and your age.

For Ottawa to have some kind of cookie-cutter solution or a panel to decide this, my goodness, you might as well keep the law the way it is, because the end result would be the same. People would not be able to access physician-assisted death, they would take actions on their own, and they would suffer in the interim.

• (1815)

Mrs. Brenda Shanahan: Thank you.

I have a question for the Council of Canadians with Disabilities. Have you thought about accessibility? Is that a concern in the measures you have proposed?

Mr. Dean Richert: Mr. Chair, if I may, I will respond to that question.

Yes, we have thought about it, and that's the reason why we were thinking about something like a consent and capacity board, which is also in Ontario, that has some access issues around it that allow a person to have almost immediate access, within 24 hours. That's why we also said in our submission and in our brief that it could be without an oral hearing. It could be done by affidavit or it could be done by simply submitting the paperwork from your physician and two physicians. A physician can do the vulnerability assessment. They would submit it to a panel. It would be, if I recall correctly, like a Dr. Low situation. There could be a turnaround in a very short period of time, where no one has to appear in front of a panel.

We have thought about access, and access is a real issue. Listen, the CCD is very aware that people need access. For us, accessibility has been a concern throughout our history as the CCD and this is also a place where we want to make sure that there is quick access, but we also realize that we don't want to put doctors in a position of having to make the decision. If the doctor you are going to, your family physician, is one who has a conscientious objection to facilitating or preparing the documents, this leaves them still available to be with the person who is their patient, to continue on, and to be close to them.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you very much.

I will now turn to Ms. Harder.

Ms. Rachael Harder (Lethbridge, CPC): My first question is for Linda.

Linda, I hope you can clarify for me the question that was asked in the Ipsos Reid poll. Do you have the exact question there?

Ms. Linda Jarrett: I do. The question on the Ipsos Reid poll was as follows: "As long as there are strong safeguards in place, how

much do you agree or disagree that a doctor should be able to help someone end their life if the person is a competent adult who is terminally ill, suffering unbearably and repeatedly asks for assistance to die?"

Ms. Rachael Harder: Just help me understand what people's response options were to that question.

Ms. Linda Jarrett: From the information I was given, 85% of people in that category, meaning people with disabilities, agreed or strongly agreed to the right to physician-assisted dying. That was the information I was given.

• (1820)

Ms. Rachael Harder: Thank you.

Ms. Linda Jarrett: You're welcome.

Ms. Rachael Harder: I have another question here, and it's for the council.

Dean and Rhonda, your organization has expressed that it disagrees, actually, with the findings of the Ipsos poll. I'm wondering if you can very quickly address the concern you have with regard to the findings of this poll.

Mr. Dean Richert: This is a poll that was done prior to the decision that came out of Carter, correct? This poll was done in the fall of 2014.

Ms. Rachael Harder: I believe that's correct.

Mr. Dean Richert: Right.

This poll was commissioned by Dying With Dignity, I think through Ipsos Reid. I don't have it in front of me, so I can't speak directly to it. I know we have some paperwork on the reasons why we have disagreed with those findings.

If you want that, and if it would be helpful, we can supply that to the committee if you don't have it in front of you.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): That would be great.

Mr. Dean Richert: I can't speak to it now, just because I don't have that paperwork in front of me.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): You can follow up with the clerk. Thank you.

Ms. Harder.

Ms. Rachael Harder: Dean and Rhonda, I have another question for you. It's been stated on a number of different fronts from your organization that you disagreed with the provincial-territorial expert advisory group. I'm just wondering if you can share with me your experience there.

I have a two-part question. First, I'd like you to talk a little bit about how you thought you were treated or corresponded with by this group, and then I would like you to answer for me what safeguards you feel are necessary for persons with disabilities going forward.

Mr. Dean Richert: Neither Rhonda nor I were there to speak to the panel, but certainly we can get you information on that.

I think either John Hicks or Amy Hasbrouck spoke to the panel on that issue.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Perhaps you could get that information to the clerk.

Could you answer the second part of the question?

Mr. Dean Richert: Could we have that question repeated, please?

Ms. Rachael Harder: I'm just wondering if you can outline for us the safeguards that you believe the people within your organization are asking parliamentarians for.

Mr. Dean Richert: On the types of safeguards we're asking for, we would look for definitions of the criteria. We would be asking for the definitions of the criteria in the legislation, the criteria outlined by Carter in particular, and of what is a "grievous and irremediable" condition that causes enduring suffering. We would be indicating that it should be only for competent adults with a grievous and irremediable condition.

We also agree that palliative care, or at least support systems, and physician-assisted suicide is one of the safeguards, so we would ask, realizing that perhaps it isn't the committee's area to be dealing with funding for palliative care, that it be part of this. If you are bringing recommendations, that would be a recommendation.

We would ask that requests for physician-assisted suicide be reviewed and authorized by an independent review panel with sufficient information to determine if the necessary criteria are met, and that in making that decision the review panel would be looking at a person's request and the reasons for the request.

As we know, the Carter case dealt specifically with the issues around vulnerability and indicated that quite clearly, in I think paragraph 76 of the decision, when it agreed with Justice Sopinka in his saying in Rodriguez that he notes sections 14 and 241 of the Criminal Code are "grounded in the state interest in protecting life and [reflect] the policy of the state that human life should not be depreciated by allowing life to be taken".

These are the reasons why we think we'd look at the reasons for requests: what are the reasons for the request?

Thank you.

• (1825)

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you.

Mr. Rankin.

Mr. Murray Rankin (Victoria, NDP): I would very much like to say to you, Mr. Fletcher, how much I appreciate your very candid and moving presentation. I look forward to getting your book.

We have a conflict, I think, between what your vision is of the safeguards we need and what we heard from the Council of Canadians with Disabilities. I want to put that on the table. You're asking for it to be very simple and to simply track the language of the Supreme Court of Canada in Carter. You say "don't make it complicated", whereas the CCD has talked about the need for a review board process, a federally appointed judge, 45 days, and the like.

First, I'd like to hear your response to that proposal, and then I'd like to hear from the CCD on this prior review notion.

Hon. Steven Fletcher: Access delayed is access denied. There are many caveats and many obstacles that were described by the CCD, which, by the way, is a great organization. They have done great work, but on this.... I'm not in Parliament now, but I've been in Parliament long enough to know that Ottawa could really screw this up by putting in too much red tape and by making assumptions about what people feel about life and what quality of life is.

You cannot have a cookie-cutter solution when you are dealing with individuals. Doctors deal with individual cases all the time. I believe the chair of the committee is an oncologist. Are there two cases that are identical? Of course not.

The further you move away from the Carter decision, the more likely it is that you're going to step into provincial jurisdiction. When you make that step, I predict you'll go into constitutional darkness, never to be found again. That is just the reality.

For health, for palliative care, of course we should put in as many resources...but that is a provincial area of responsibility and provinces need to decide how they're going to use the monies they receive from the taxpayers and make decisions accordingly.

Mr. Murray Rankin: You would reject the notion of a review board as described by the CCD.

Hon. Steven Fletcher: I would, though in my bill.... Of course, you could always take the wording in my bill and just insert it. It's very well worded.

Voices: Oh, oh!

Hon. Steven Fletcher: There is a review in it that would take away anyone who has a vested interest in having someone pass on. That includes family or the institution a person may be in. You don't want the institution saying, "Well, we need to clear out bed 15." There has to be an arm's-length process, I believe, but I don't think it's up to Ottawa to decide. It should be the provinces that form that.

Yes, it will be a patchwork and it won't be unified, but that's our health care system.

Mr. Murray Rankin: Thank you.

In the time available, I wonder if I could ask the CCD if they wish to respond to what Mr. Fletcher said, specifically about the need for a review board.

Mr. Dean Richert: A review board process will honour the differences and won't be cookie-cutter. The access can be quite quick. As we know with the care and consent board in Ontario, you can have access within 24 hours. We're saying that it doesn't have to be by way of oral evidence, so it can be very quick. It's not cookie-cutter at all.

We agree that if you meet the criteria like a Dr. Low, this isn't a situation where you're waiting 45 days. This is a situation where you're in and out, where a doctor will say, yes, not vulnerable. He's requested it and two physicians have said yes. They've done a capacity assessment. They've done a consent assessment: done. Send it to the board: done. The doctor, if they have a conscientious objection, now cannot object to that. They send it to a review board process.

I can imagine it taking very little time to do that, very little time.

• (1830)

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you very much.

Colleagues, do I have agreement from you to allow two more questions? I can tell you that our next panel has agreed to a slight extension in their time. Are you prepared to allow two more questions?

Voices: Agreed.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you very much.

Senator Nancy Ruth.

Hon. Nancy Ruth (Senator, Ontario (Cluny), C): To the council on disabilities, you've said that a vulnerability assessment should be mandated.

I wonder if you could tell us, of the countries that allow some sort of physician-assisted dying, whether it's in Europe or the United States, whether any of them require either a mandatory vulnerability assessment or advance authorization by an independent party. Are there any models for this anywhere else in the world?

Mr. Dean Richert: David Baker can possibly speak to that. I think Colombia's supreme court has just recently indicated.... They used to have physician-assisted dying without a prior review process. But David Baker, who's speaking later on, can speak to that issue.

In terms of a vulnerability assessment, doctors do that right now. Doctors do a vulnerability assessment right now, or that's my understanding. If you have a case where you have a person who wants to withhold or withdraw life-sustaining treatment, a doctor will do a vulnerability assessment on that person, dealing with capacity issues. Capacity and consent—that's for vulnerability. We're not saying that an independent, qualified expert needs to come in every time and deal with a vulnerability assessment. We're saying that if there's smoke, there should be some deeper reasons for it. If a doctor says there's no smoke here, there's no smoke. They've done the vulnerability assessment.

Hon. Nancy Ruth: What you have said, though, is that apart from some legislation that may be coming forward in Colombia, there are no existing models of this. My comment is, why put it on Canadians?

In terms of informed consent, you did say that it may require someone else to do this other than the physician, although you've just said that physicians go ahead and do this now. Why would there need to be another—

Mr. Dean Richert: If I can, Mr. Chair, I'd like to answer that question.

The reason there would be is so the instance of suicidal ideation doesn't come out of the disability. For instance, if I have type 1 diabetes and I now have to take insulin five times a day, my end organs are involved, I am legally blind, and that's the reason I want to die, what supports are there? What family doctor may be able to tell me what all of the supports are? If I'm looking at informed consent, which is what is necessary in this particular situation, I think informed consent should involve these other support issues. At the end of the day, I may still decide, as a type 1 diabetic who's aged 55, that I want to die and that I still want physician-assisted dying. That's something where I may have a grievous and irremediable condition, enduring suffering, and I don't want to live this way anymore. I may actually deal with that issue in that way. A doctor may say, "I think there's smoke here. I think you should look at other options." Or a doctor may say, "Yes. Okay."

That's what we're asking for. A doctor may not have all of the understanding around him or her to deal with those issues.

Hon. Nancy Ruth: I'm sure that is always so. I'm someone with type 2 diabetes who is going blind and I can assure you my doctors of various kinds tell me where to go for low-vision clinics and all kinds of other things, and what foods to eat and not eat. There are supports out there. With regard to the example you used, these people who get insulin have medical consultants.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you.

The final question goes to Mr. Arseneault.

[Translation]

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

My question is for the Honourable Steven Fletcher.

[English]

I can ask the question in English if you prefer.

Hon. Steven Fletcher: You'll get a better answer.

Mr. René Arseneault: As I read your proposed Bill C-581, could you comment on the fact that there would be 14 days, if I read well, between the demand for the physician-assisted death and the act itself?

• (1835)

Hon. Steven Fletcher: What the member is referring to is that between the request and the action, I put in a 14-day span, so if the individual in any way said that they wanted to live, that would nullify the physician-assisted death request. Some people wanted it to be seven days or 24 hours, and some people wanted it to be years, but this is one of the key issues. How far in advance can a request be made, and what will be tolerable in the Criminal Code as far as living wills go?

That is a Criminal Code issue. If this committee could come up with a consensus, and I think it would be in such form that in a decade or whatever you would have to renew it, most Canadians would be in favour of that and would find peace of mind, especially with all the terrible things we hear about dementia, brain injuries, stroke, and so on.

That would be a helpful suggestion from the committee, but telling provinces what they can and cannot do is a slippery slope.

I will say just one more thing. To emphasize the importance of the framework of the Supreme Court decision, the committee can suggest raising the penalty. If you go outside of the 18-year-old competent adult, you're going to go to jail for a long time. That would be a very good countermeasure to make sure people follow the intent of what the Supreme Court has suggested.

Mr. René Arseneault: I don't want to go back to exactly what my colleague Mr. Rankin asked you before, but I am going to ask you this. You recommended that the federal government take a minimal role and leave details to the province. The foremost authority on constitutional law in Canada, Professor Hogg, who we heard here, warned us against assuming that all provinces would act, and he recommended that the federal government set forth a detailed regime that would apply only if any given province did not legislate.

Do you agree that this would be preferable to having patients or doctors shop for the province that has the rules they would prefer?

Hon. Steven Fletcher: Legislation is not necessary. The Supreme Court ruling stands on its own: you have to be 18 and a cognitive adult. There are all sorts of other issues that the Supreme Court took into consideration when making these decisions. I suggest that everyone on the committee read the Supreme Court decision and the references. You will see what the big issue is: what is a competent adult?

What's intolerable suffering to me may not be acceptable to you, and my religious views may not be compatible with yours, but we're all individuals, and with this, we will be able to empower people to live full and meaningful lives right to the last moment, and the state will provide the resources to that last moment. That is the goal, so please don't try to tell people what they can or cannot do with their lives or tell them what quality of life they have or don't. Just let the people.... Trust the individual, the competent Canadian.

By the way, everything you decide here will affect every Canadian who is alive and every Canadian there will be in the future, and it will probably set the framework for the western world, so think about it.

• (1840)

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you very much.

I want to express my gratitude to the remarkable Canadians who have appeared before the committee this evening. On behalf of all my colleagues, I thank you for your appearance here and for your dialogue with us.

With that, I am going to suspend the meeting for two minutes. We need to have a quick turnaround for the next session.

_____ (Pause) _____

• (1845)

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): We are back in session. Please assume your positions. We are going to begin.

Mr. Lemmens was here a minute ago. I know Mr. Lemmens is in the building, so we will not start with that pair, and I will begin the presentations with Ms. Downie.

I want to remind both groups that you have a total of 10 minutes. Mr. Baker and Mr. Lemmens will have 10 minutes in total. Ms. Downie, you have 10 minutes.

We will begin. This session is scheduled to end at quarter to eight. Thank you.

Prof. Jocelyn Downie (Professor, Faculties of Law and Medicine, Dalhousie University, As an Individual): Good evening. Thank you for inviting me to speak with you today. I'm grateful for the opportunity to be a part of this critical conversation.

I should note here that I've played a variety of roles in various initiatives to advance end-of-life law reform in Canada. Today, however, I speak only on my own behalf as a legal academic who has been researching and writing about assisted death in Canada and abroad for more than 20 years.

Given the time constraints, I'll jump right to the heart of the matter.

I would argue that in order to have the properly administered regulatory regime for medically assisted death called for by the Supreme Court of Canada in Carter, the following need to be established through federal, provincial, and territorial legislation and health professional self-regulation: definitions of some key incontestable terms; criteria for access to medically assisted death; processes for ensuring criteria have been met; access for rural and remote contexts, and in the face of conscientious objections by institutions and providers; and oversight.

Other issues that need to be addressed also include liability insurance; life insurance; medical certificates of death; good faith immunity; and, perhaps most importantly of all, access to palliative care.

Of course, the federal Parliament cannot do all of these things, so you need to focus on what you can do. Again, given time constraints, I'm going to focus my remarks on what you can and, I would argue, should do under the federal criminal law power. You can—and I would argue should—exercise the federal criminal law power to design and implement a robust regulatory framework that, first, respects the autonomy of capable individuals making free and informed decisions with respect to medically assisted death; second, protects vulnerable persons from being induced to end their lives at a time of weakness; third, enhances access to medically assisted death; and fourth, ensures that the system of medically assisted death in Canada is well monitored.

Allow me to propose some key elements of such a framework. The first is definitions of terms.

Medically assisted death: I would define this as medically assisted suicide and voluntary euthanasia that is performed by a physician, by another health care provider acting under the direction of a physician, or by a nurse practitioner. This clarifies that the Criminal Code exception covers both assisted suicide and voluntary euthanasia, as is required by Carter, and it resolves the issue of who is protected under the Criminal Code exception in a manner that retains an appropriate level of professional competency and accountability while also ensuring access, especially in rural and remote communities where there may be no physicians. Assistance: I would define this explicitly as the provision of a prescription for a lethal dose of medication or a lethal injection for the purpose of medically assisted death. This clarifies that providing supporting services—for example, a pharmacist filling a prescription—during the delivery of medically assisted death does not constitute providing medically assisted death and therefore does not violate the Criminal Code. This will prevent exposing people who provide such services to liability and will prevent people from declining to provide such services because of fear of liability.

Grievous: I would recommend that you use its established definition in law and common usage, which is "very severe or serious". Do define it so as to make the meaning clear and to prevent it from being narrowed inconsistently or inappropriately by provincial-territorial legislative assemblies or by regulatory colleges. Do not define it through a list of conditions, because you cannot possibly anticipate every condition, and many conditions are only sometimes grievous.

Irremediable: I would codify the subjective aspect that the Supreme Court established. As the Supreme Court said, it means that the condition cannot be alleviated by a means acceptable to the person.

Mature minor: this is a person under the age of majority who has the capacity to make an informed decision about medically assisted death and sufficient independence to make a voluntary decision. This is a well-established and well-understood concept in health law and policy across Canada.

Moving from definitions of terms, we come to the second key element: criteria for access. Access should be limited to those who have "a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual", based on their assessment of their personal circumstances. This is Carter.

Terminal illness should not be an inclusion criterion. It was not included by the Supreme Court in Carter. It is too vague and indeterminate. It is arbitrary and it has no moral justification as a barrier to access.

A specific age should not be an inclusion criterion. Although the Supreme Court used the word "adult", it did not define it intentionally—and in law the word "adult" has been defined in various statutes and the common law as a variety of ages not limited to 18 or 19.

• (1850)

It is also important to note that across Canada, it is well established that individuals under the age of majority have the authority to make health care decisions, even if the consequence will be death. It's also important to note that the Supreme Court, in A.C., held that an "irrebuttable presumption of incapacity" for medical decision-making based on age violates the charter. First, then, it doesn't violate Carter to include mature minors. Second, even if Carter only held the Criminal Code prohibitions to be invalid for individuals over the age of majority, Carter sets a floor and not a ceiling, and the issue of minors was not before the court. The third and most important point is that to exclude individuals on the basis of a specific age flies in the face of established health law, policy, practice, and the charter.

Next, mental illness should not be an exclusion criterion. It was not excluded by the Supreme Court, and not all individuals with mental illness are incompetent. Physicians already routinely determine whether someone is competent, even when they have a mental illness. Furthermore, the suffering that can accompany mental illness can be as excruciating as any suffering that can accompany physical illness. Finally, I would argue that excluding individuals on the basis of mental illness would violate the charter.

Before moving on to procedural safeguards, I should say a few words about when the individual must meet the criteria for access. This is what you've been discussing as the "advance directives" issue. The questions are these: what criteria do you need to meet to make a valid request for an assisted death, and what criteria do you need to still have at the time of the provision of assistance?

I would suggest that the best position to take at this time is to require the following: at the time of the request, the patient must have a grievous and irremediable condition and be competent, and at the time of the provision of assistance, the patient must still have a grievous and irremediable condition and be experiencing intolerable suffering by the standards set by the patient at the time or prior to losing capacity.

This approach prevents the tragic case of someone having met all of the criteria but being denied medically assisted death because they became incompetent just before it could be provided. This approach also prevents someone killing themselves earlier than they otherwise would for fear of becoming incompetent before reaching the point of intolerable suffering. One example is a person with progressive dementia.

Finally, this approach allows for the consent process to happen before someone is actually experiencing intolerable suffering. It seems cruel to require the person to be actively experiencing intolerable suffering throughout the process of assessing the criteria, including, perhaps, a waiting period.

Moving from criteria for access to the third key element, procedural safeguards, here we turn to rules with respect to consent, capacity assessments, documentation, reporting, and other procedural safeguards. This is, of course, the area with the greatest overlap in jurisdiction with the provinces and territories. However, for a number of reasons, I would argue for federal action here, tied closely to the criminal prohibitions and exceptions.

The first reason is to ensure consistency in approach across Canada. The recent federal-provincial-territorial ministers of health meeting does not instill confidence that they will come out with a harmonized approach. The second is to prevent gaps in coverage if some provinces and territories do not legislate. There is a real risk that some provinces and territories will not legislate but will just leave this matter to the colleges, which have already shown themselves to not be willing to adopt a harmonized approach. Their newly developed standards are an absolute patchwork.

The fourth key element is oversight.

We need two levels of oversight. The first is retrospective case review. For this I would recommend a regional review committee system to retrospectively review all cases of medically assisted death to determine compliance with the new rules. The second is oversight of the regulatory framework itself. For example, it would ensure data collection, analysis, and reporting. It would commission research to ensure ongoing, evidence-based policy-making, and it would make recommendations to the minister about potential law and policy reform with respect to medically assisted death in Canada. For this I would recommend the creation of a national oversight commission for medically assisted death.

Finally, there's the substantial similarity provision. This would allow provinces and territories that wish to design and implement or, in the case of Quebec, keep—their own regimes to do so as long as these regimes were substantially similar to the federal regime. This respects the fact of overlapping federal-provincial-territorial jurisdiction, assures a level of harmonization across the country in relation to the core elements of the exception to the Criminal Code prohibition, and prevents gaps if some provinces and territories fail to legislate. In Canadian law, this is an established way of responding to situations of overlapping jurisdiction, such as this one.

• (1855)

With that, my time is up. I thank you for your attention, and I welcome your questions after the next presentations.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you very much.

I'm now going to turn to Mr. Baker and Mr. Lemmens.

I understand you'll present, Mr. Baker.

Mr. David Baker (Lawyer, Bakerlaw, As an Individual): I'm going to make a preliminary comment and then turn things over to Professor Lemmens for a brief comment concerning the situation in Belgium and the Netherlands, which represents the model that has just been recommended by Professor Downie. I will then speak to the draft legislation, which you have in the blue volume, which is tabbed. I hope you all have that available to you. I will very briefly highlight the differences between what Professor Downie has just indicated and what we would be recommending.

Let me say first of all that when we initially applied to appear before you, Mr. Gilbert Sharpe was one of the three who together made the application. He is not here. He is truly the father of law in medicine in this country. He has drafted most of the important health legislation in this country. He drafted the mental disorder sections in the Criminal Code, which in many ways are parallels to what we are talking about here, which is a carve-out from the Criminal Code. He has vast experience. He would have spoken to you about how the panel of review, the review board, would have meant that physicians, including family physicians, would not have disqualified themselves from the process for moral objections because they would not be making the decision. That is the objection that the physicians. There are at least 18 mandatory reporting functions from which there are no moral objections taken.

I'll turn it over to Professor Lemmens.

Prof. Trudo Lemmens (Professor, Faculty of Law and Dalla Lana School of Public Health, University of Toronto, As an Individual): In Carter, the court actually explicitly stated that Canada could avoid any of the problems Belgium is facing in the context of physician-assisted dying by adopting a strict regulatory regime that allows for less discretion. I noticed with some disappointment that the provincial-territorial advisory group now recommends a regime that is more flexible, less restrictive, and more open-ended than even the Belgian system. I invite you, therefore, to look in more detail at the documented cases and evidence about problems in the Belgian system, which I've documented in this memo, in order for you to fully understand the risk associated with a flexible and open-ended system. I have a more detailed chapter that I can share later with the committee as well.

I can only talk about the essence because I want to give more time for the proposal, but the essence is this: even if, in Belgium, physician-assisted dying requests are to be granted only when certain conditions are met, the vague and flexible criteria, coupled with the significant powers vested in physicians, have resulted in what I would call a quite open-ended access regime.

Individual physicians are the main gatekeepers, but their tools of competency assessment and informed consent assessment are questionable and difficult. There are documented cases of how it may not work in the Belgian system. More than 70% of the physician-assisted dying requests are now granted in Belgium, which is a significant increase over time.

In Belgium, physician-assisted dying has expanded beyond the original intentions of offering compassionate access and exceptional care. The numbers give you an indication. We have gone from 347 cases in 2004 to 2,021 cases in 2015, the latest number, but numbers tell us only so much. Obviously these could all be valuable cases, but they do suggest a normalization of the practice.

I want to emphasize, as I do in the memo, that it is actually more interesting to look at the areas in which physician-assisted suicide has expanded. I'm not saying that these are the majority of the cases, but these are cases that the committee should be aware of. It has expanded in areas that are more problematic and a bit more existential, such as suffering cases and also, increasingly, mental health. This expansion affects people who are experiencing lifechanging disabilities; situations of loneliness, isolation, societal stigmatization, and rejection; difficulties with managing daily activities; and difficulties functioning independently. In those situations, good support measures and structures can prevent premature death, while all-too-easy access to physician-assisted dying can incite life-ending requests.

I won't discuss the many publicized cases in the memo that you have in front of you, which have been quite widely advertised, but I will say that these are not just anecdotal cases. They are actually real and lived physician-assisted dying experiences, which in some cases we have seen documented in detail. These are the publicly known cases.

In my main memo, I pay more attention to a less publicly discussed aspect: euthanasia in the context of mental health. I invite the committee to read this discussion in detail. When physicianassisted dying is defended in the context of mental health, it's often presented that PAD is only necessary and will only happen in exceptional cases of untreatable chronic depression, where physician-assisted dying is the only compassionate option, but reports in Belgium may surprise you. Also, ongoing research about practices in the Netherlands show that it now involves people suffering from personality disorders, post-traumatic stress, anxiety, eating disorders, schizophrenia, addiction, autism, and even profound grief. In most instances, according to ongoing research, it involved socially isolated, lonely people. In some cases, depressed people were euthanized without close family members even being alerted about the euthanasia request.

Reports have also raised questions about the safeguards in place. Again, you have documentation about that. I indicate why competency assessment is a notoriously problematic tool in very complex areas of mental health in particular, but certainly also in the context of disability, because, for example, it is influenced by the values of the physicians.

In Belgium, you have a small group of very committed physicians who are committed to physician-assisted dying and who by nature may be tempted to much more easily conclude that patients who are requesting access to physician-assisted dying are competent, and thus we see their lives being terminated.

There are also questions in many of these cases about how treatment resistance has been determined. Physicians may easily presume that people are treatment resistant, but this is a notoriously difficult thing to assess in the context of mental health, and it actually has been widely questioned.

I also discuss the limits of the reporting system with respect to the fact that there is still under-reporting, and also with respect to the fact that the reporting can actually give us the wrong sense of security. People are not looking sufficiently at exactly what is happening in individual cases, as is described in my memo. I won't expand on that here.

• (1900)

I will now turn it over to my colleague.

Mr. David Baker: I want to reiterate a point made by the CCD to you, which is that while there is strong support in polls for physician-assisted dying—and that is not the issue, the Supreme Court having spoken—there are only two polls of which we are aware that address the issue of safeguards. They are the CARP poll, which has been mentioned in the papers recently, in which a majority of people said a panel, a prior review, rather than an *ex post facto* or after-death review, was appropriate, and that of the federal panel, which conducted its own review and found that more than 50% supported review by a panel before the death occurred, rather than after death, as occurs in Belgium, amongst others.

Senator Nancy Ruth wanted to put it in an international context. The American experience is not relevant to you, because in the American states this applies only to people in the last six months of their lives. It's a completely different issue. There are examples, and Colombia is the best one. There the Constitutional Court of Colombia, in December of 2014, said they were wrong in 1997 to say that this should happen with physicians' involvement only, and they now have required that prior review be put in place. That was done in May of 2015. You heard this from your justice advisers. The U.K. model, as you also heard from the justice advisers, also involved a prior review.

I would like to highlight two things and then invite your questions. Could you turn to the first tab in that blue volume? This is a piece of legislation that was drafted by me and Gilbert Sharpe for your assistance. It has actually been available since June of last year. I would be happy to answer any comments or questions that may arise from it.

What I would like to highlight first of all are the definitions of "informed consent" and the definition of "quality of life".

First of all, in regard to informed consent, as the CCD indicated, in situations where one is talking about the withdrawal of lifesustaining treatment, as Mr. Fletcher did in his personal situation, the process is not as simple as "two physicians". In those situations, there are social workers and there are case managers. There are nonphysicians involved in the process of informing people about the issues that are of uppermost concern to them, as they would have been for Mr. Fletcher.

If we can turn to "quality of life care" on the next page, page 3, at the bottom, this language in (a) through (g) comes from the trial decision of Justice Smith. This is the only place in the Carter decision where people who subsequently were assisted to die indicated why they wanted to die. These are the issues: loss of autonomy; ability to engage in activities to make life enjoyable; loss of dignity; loss of control of bodily functions; perceptions that care requirements represent a burden for family, friends, or caregivers; pain control, including access to proportionate palliative care and/or hospice care; and concerns about the financial implications of care that is not an insured service.

This is crucial language, because these are the issues that cause people to seek assistance. These are not treatment issues. These are not issues in which doctors are involved. These are the issues in which counsellors and case managers are involved in addressing such questions as, Where am I going to live? How am I going to be transported? How am I going to go to the bathroom?

These issues are the issues that we say should be incorporated into the idea of informed consent, because that is why people seek assisted dying. Physicians are not the ones—and they would be the first to acknowledge this—who are in a position to address these issues. We do not say this is an issue that should be imposed on persons in late stages of life, when the options or choices are very few. One final point, which I would emphasize, is that the bill addresses the access question. The bill imposes the obligation on the attending physician or the family doctor who is approached to initiate the process and see that the process goes to review. It is not a process for screening out applications, and the applications can proceed, in a case such as Dr. Low's, on an expedited basis within a matter of days, as review boards can do. The requirement set out here is that there be a maximum of 45 days. This is not an issue. Access is not an issue under this proposal.

• (1910)

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you very much.

Ms. Dabrusin.

Ms. Julie Dabrusin (Toronto—Danforth, Lib.): I have a question for Ms. Downie.

An area that has come up several times today as well is the issue of people in transition. When a person is rendered paraplegic or paralyzed, there's that period of trauma immediately after the injury when that person may be requesting physician-assisted dying. I was wondering if you could comment on how you see the Carter test applying to that scenario.

Prof. Jocelyn Downie: Sure. I think the concern people are expressing is understandable, but I think it absolutely can be dealt with by reflecting on the Carter test, and also in the context of the practice of medicine.

Think about what "informed choice" requires. The individual has to have capacity, under the Carter test, which means they have to understand the nature and the consequences of the decision to be made. In the immediate aftermath of a traumatic injury, physicians will say a person doesn't actually have that yet, so being responsive to that kind of situation is built into the test.

Similarly, you have to be informed. You could argue again that in the immediate aftermath of an injury, you don't yet have the full information about what it is going to be like to live in that way, so you would again maybe not be found to be fully informed.

Under the Carter test, the suffering also has to be enduring. In the immediate days after an accident, no physician is likely to say that the suffering is enduring and that someone therefore meets the test.

The final thing to say in response to this is that physicians already, every day, deal with exactly this kind of scenario in relation to refusals of treatment. You can have somebody who has a traumatic injury, and then they say the kinds of things that Steven Fletcher may have: "I don't want the treatment. I don't want a ventilator. I don't want artificial hydration or nutrition." We work with the established principles of informed choice and insist that the person have capacity and be informed, and that can take time.

You don't have people losing their ventilator or having antibiotics withheld in the immediate aftermath of a traumatic injury. I'm saying it can absolutely be managed in the context of current practice. We rely on physicians to do that now, and Justice Smith acknowledged this in her trial decision. Mr. David Baker: May I say-

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): No.

Ms. Dabrusin, you direct the question. If you want Mr. Baker to answer, you direct it. The question is to you.

Ms. Julie Dabrusin: I actually just wanted to follow up. You mentioned that Justice Smith had dealt with this in her decision. Can you elaborate on that for me, please?

Prof. Jocelyn Downie: Yes, and it's important in relation to what Professor Lemmens said.

The evidence about the challenges in competency assessments was before Justice Smith and was tested in court. She concluded that we trust physicians now to make these complex decisions all the time in relation to refusals of treatment. She said there is no basis for deciding that they are capable of making those assessments in the context of withholding or withdrawing life-sustaining treatment but not in the context of assisted dying. She concluded that the system we have, in which we trust physicians to make these complex decisions in the context of withholding and withdrawing treatment, applies equally in assisted dying, and we should continue.

That is not to say we have perfection around competency assessments, but it is to say there's no morally sustainable difference between the withholding or withdrawal on the one side and assisted death on the other side with respect to capacity. We just have to do it better in relation to both, but we trust the physicians and we should stick with the same system that we have now.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): You have one minute.

Ms. Julie Dabrusin: I think my friend Mr. Aldag wants to ask one more question on that point.

Mr. John Aldag (Cloverdale—Langley City, Lib.): I don't know if we can do it in one minute, but we'll try. If not, we'll perhaps come back to it.

I want to explore "irremediable", particularly as it relates to mental illness. We heard last night that mental illness is irremediable. I think it is something we're going to have to struggle with.

In your paper, you talk about the floor-to-ceiling terminology. I'd like to hear, from your perspective, whether mental illness falls below the floor. Is it at the floor level? Is it somewhere in that ceiling level? Are there considerations concerning mental illness that—

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): I think she has enough there.

Mr. John Aldag: Okay.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): You're on the list for later.

Prof. Jocelyn Downie: First, as to whether mental health has exclusion criteria below the floor, I think it would go below the floor that is required by Carter. It was in front of Carter, and these questions and concerns about mental illness were absolutely in front of the trial judge. All the evidence from Belgium was also there. The court did not make mental illness an exclusion criterion. I would say it is absolutely below the floor of Carter, so I think it's outside your....

Actually, you can't go there. If you go there, to use the expression that constitutional lawyers like, you'll "Bedford" Carter, which means you will go below what Carter told you that you could do, and it will be unconstitutional.

In terms of "irremediable", I watched last night when that was being talked about. I have to say that there's a clause missing in the conversation about this point. The court didn't end with "irremediable"; it said irremediable means it cannot be remediated or alleviated by any means acceptable to the patient. Therefore, while you may say that a certain condition is treatable, it can be irremediable if the treatment is unacceptable to the patient. That's precisely what you see in the context of mental health, as well as many other conditions, but absolutely in the context of mental health.

I think that would resolve the confusion that came up yesterday in the psychiatric association conversation.

• (1915)

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you very much.

Monsieur Deltell, please go ahead. You're sharing your time with Mr. Cooper.

Mr. Gérard Deltell (Louis-Saint-Laurent, CPC): Thank you so much, Chairman.

Gentlemen, madame, be welcome in your Parliament.

[Translation]

We are here to help the government define its legislation.

[English]

We need to know exactly where to go in terms of comparing the Criminal Code with the provincial powers. The health care system belongs to the provinces and the Criminal Code belongs to the federal government.

My question is very precise, and I would like a quick answer in order to let my colleague Mr. Cooper ask you a better question than mine. I'd like to know what the limit is. Should the federal government indicate clearly where the provinces could go or let the provinces decide by themselves?

Madame Downie.

Prof. Jocelyn Downie: I don't think the federal government should let the provinces go at it now, because they have not given you sufficient indication that they will actually do it in a harmonized fashion, or at all. This means, I think, that the basics have to be put in place by the federal government. I think you can do it under your constitutional powers because you have the prohibition under the Criminal Code. Then you can have regulations under that.

Absolutely you need to regulate this area. You can't regulate everything, but you need to regulate what's in the draft bill that I submitted to you.

Mr. David Baker: We agree with that. It is a rejection of what is in the provincial-territorial report, which is a welcome change, and it is consistent with Professor Hogg's advice to you in terms of the constitutional division of powers. Also, the draft bill you have from us incorporates all of the language of Bill 52, and it is intended so as to not require amendment of Bill 52.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Mr. Cooper.

Mr. Michael Cooper (St. Albert—Edmonton, CPC): Thanks, Mr. Chair.

Mr. Baker, it is your recommendation, as well as Mr. Sharpe's recommendation, that the oversight authorization body be the review boards that have already been established under section 672.38 of the Criminal Code and that are operational in all 10 provinces.

Could you perhaps elaborate on what the features are of these review boards that in your opinion make them most suitable to make decisions with respect to this question?

Mr. David Baker: First of all, unlike any other review board structure, this is the only one that exists in every province and every territory. It is required under the Criminal Code provisions.

Second, we are talking about respecting the fact that these decisions are significantly different from the review board under the Criminal Code. The province names the board, and would appropriately rename the board to include the additional mandate. The composition is chaired by a superior court judge. As indicated by CCD, we feel that is essential. Why? It is so that there are written reasons that provide precedent, which means that cases do not need to go to hearings and review boards. The guidance is available to enable physicians to appropriately bring forward those situations that are mandated under the Carter case for a decision.

Consistency exists now. The provinces appoint all of the members. The province names the board. The board is available and goes to the person who requires the hearing where an oral hearing is required. Plus, of course, it has passed the constitutional muster of having been in the Criminal Code for many years now without any challenge, and it addresses significant issues such as treatment.

Professor Lemmens.

• (1920)

Prof. Trudo Lemmens: If I may add to that, it's actually something that appealed to me in this proposal as well, because I've looked at the Belgian situation, and one of the problems that we have in certain areas of practice of physician-assisted dying in Belgium is that there is a small concentration involving a couple of practitioners who are very committed to providing access to physician-assisted dying. For example, in the report that I cited on euthanasia cases in Belgium, there's a published study in the British medical journal *BMJ Open*, the first author of which was herself involved as a consultant in probably the majority of physician-assisted dying cases involving psychiatric patients over the period of the study. In other words, in a system that really relies on physicians, you can have three or four physicians who really take the liberty of providing access in a way that most Canadians would agree would not be appropriate.

In this particular system you have consistency, you have judicial oversight, and you actually have restrictions about how individual physicians may respond. There are very many good physicians out there, but if you talk to any physician, you'll hear that there are sloppy people out there who may not take appropriate care and who may actually be careless in the way they provide access and even be so ideologically committed that they think this is the best thing to do for everybody who is suffering from very severe mental illness.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you.

Mr. Rankin.

Mr. Murray Rankin: Thank you, sir.

Thank you, witnesses, for the excellent presentations.

I have only a couple of minutes, so I'm going to go quickly and ask Professor Downie something first.

The material that was provided by Mr. Baker and Mr. Lemmens talks about two doctors, one a responsible physician and one a consulting physician who must be a specialist, if I'm understanding correctly. I'd like your reaction to that proposal. Is it a good idea, bad idea, or necessary idea?

Prof. Jocelyn Downie: I think it is going too far, because not in all circumstances would you require a specialist, particularly if the specialist is required to be a psychiatrist. There may be times when you need a specialist. That is when a physician, whether the first or the second physician, is not confident they can assess whether the criteria have been met or not, and so they would then get a second opinion, which is what they do all the time, so I would revert to standard medical practice on that.

Mr. Murray Rankin: I'd like to ask both Mr. Baker and Ms. Downie this question.

A person who was recently diagnosed—we heard about this from Mr. Fletcher—is very vulnerable and very often suicidal in the first two, three, or even four or five years, and the claim is that such a person should not be allowed in those circumstances, for that period of time, to acquire this service.

I'd like each of you to comment on that.

Mr. David Baker: I would point out first of all at tab 4 of our material the chapter from Tom Shakespeare, which was put into

evidence by the applicants in the Carter case. This was the evidence they advanced with regard to safeguards, where Mr. Shakespeare says that for people in this transitional period, which I believe was being referred to earlier, it is not an appropriate time. It is a period of vulnerability. This is referred to by the court. It is the intention of the court that the issue of vulnerability be addressed.

It is not addressed in Belgium. It is not addressed under the model proposed by Professor Downie, and, with the greatest of respect, it is addressed in the draft bill that we have presented.

Mr. Murray Rankin: Ms. Downie.

Prof. Jocelyn Downie: I would say that it is actually addressed in our standard approach to getting consent and that somebody who has had that traumatic injury and is suicidal would actually not qualify under the Carter test because they would be found not to meet the criteria.

Mr. Murray Rankin: As a matter of drafting, should we indicate a time frame, or just leave it to the physicians?

Prof. Jocelyn Downie: Absolutely leave it to the physicians, because if you indicate a time frame, you do two things. One, you are treating it differently from a refusal of treatment and you have no justification for that. As well, the Carter decision at trial rejected treating things differently in that way.

Mr. Murray Rankin: You mentioned, Professor Downie, progressive dementia. I'm wondering how that would apply in these circumstances, because Carter requires that there be an injury that causes suffering that is intolerable to the individual. What if the person has dementia and isn't suffering as one would usually use that term?

Prof. Jocelyn Downie: That's why I talked about the timing of when you have to be competent. It's to suggest you could make the decision, the request, before the intolerable suffering actually arises, and in that declaration you would state what you consider to constitute intolerable suffering. Otherwise, once you're past that point, who is any of us to assess whether that person is facing intolerable suffering? It is for the person, so they dictate that in advance.

• (1925)

Mr. Murray Rankin: I would like Mr. Baker and you as well to please answer this question. On the matter of substitute decision-makers in this process, first of all, Mr. Baker, would you accept substitute decision-makers or not?

Mr. David Baker: No, and that is contrary to the Supreme Court decision that there be decisions made by substitute decision-makers. It is also contrary to Carter that advance directives, as described by Professor Downie—

Mr. Murray Rankin: Both advance directives and substitute decision-makers.

Professor Downie-

Mr. David Baker: The court says it is the person at the time that the lethal dose is being administered—that is, treatment being administered. There is a requirement of capacity at that point.

PDAM-07

Mr. Murray Rankin: Of course, you would say that this is a ceiling, not a floor—

Prof. Jocelyn Downie: I would say that they didn't say that you have to be competent at the time of the provision of assistance. That is unclear in Carter, so it needs to be set by you.

I would say no to substitute decision-makers. I don't know that anybody is advocating for that. I would also say that advance directives of the sort proposed are not inconsistent with Carter. If you look at the trial definition of voluntary euthanasia, it includes "in advance".

Mr. Murray Rankin: Now, you spoke, I think-

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Senator Seidman.

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

Dr. Downie, in your proposed legislation you define advance directives. We heard yesterday from the Canadian Medical Association. They made it clear to us that they don't believe advance directives can be easily administered.

How would you respond to that?

Prof. Jocelyn Downie: Advance directives are defined in this legislation because it is in relation to withholding or withdrawing life-sustaining treatment in palliative sedation, not in relation to assisted death. It only relates to that. It fits into that standard model across the country. We have advance directives everywhere.

I would say not to use the language of advance directives in relation to assisted death, because you don't want to move into that whole provincial-territorial regime of advance directives. You want to keep this at the federal level, so you're saying someone can make a request in advance, but you're not importing the advance directives regime that we have in Canada at the time for assisted death. You make an advance declaration. You make a declaration, a request, in advance.

It's just defined in there because I actually have provisions in relation to something other than assisted death in the statute.

Hon. Judith G. Seidman: Okay.

In your proposed federal legislative draft, you would permit health care providers, in addition to physicians, to assist deaths under the direction of physicians or nurse practitioners. Could you help us understand that? We had quite a negative response to that as well. Given that we heard that the Supreme Court ruling refers specifically to physician-assisted death, how would this cohere with that?

Prof. Jocelyn Downie: The first thing is that you look to the definition in the Carter trial decision, which is that it's a physician or other health care provider acting under the direction of a physician. I think Carter actually contemplates going beyond physicians. It uses the words "physician-assisted death", but you'll see that's why I use the language "medically assisted death". I think that is more appropriate and it's consistent with Carter.

I am suggesting going further in relation to nurse practitioners that is, heading towards ceiling rather than not going below the floor. That is because of what we heard in the context of the provincialterritorial consultations around the north and in the rural and remote communities. It's also in relation to the scope of practice that they already do, in the context that they do capacity assessments, competency assessments, and so on. That's why I have shifted my view and put that in as well.

Hon. Judith G. Seidman: Okay.

As well, Dr. Downie, yesterday we heard testimony from Dr. Monica Branigan of the Canadian Society of Palliative Care Physicians. She discussed the importance of having a national oversight organization that would be a partnership between the provinces, the territories, and the federal government. Similarly, you have a commission on end-of-life care in Canada proposed in your legislative reference. We also heard just now from the Hon. Steven Fletcher, whose bill also includes an oversight commission.

Perhaps you could help us understand how you see the oversight role of that body.

Prof. Jocelyn Downie: I think it can play a data-collection role. It is very important to have national information so you can see what's going on, track your system, and make modifications as you need to if there are any concerns that arise. We need national data on that.

I think it also can commission research. As we've seen in the Netherlands, every five years they do a broader review of end-of-life decision-making. It's not just assisted dying. It's critically important to do that. The commission could commission that.

Also, if we have access problems, you could have that commission be responsible for developing a network of providers to do education. Support of health care providers is going to be essential here, as is a network, so that we can actually enhance access. That way, it can also play the role of quality assurance with regard to the regulatory system itself. I would also say that if you don't have participation from the provinces, the regional review committee would be run by the oversight commission so that you would have oversight of specific cases, a retrospective case review, happening as well.

I'll make a quick comment, if I may, on the issue of the provincial and federal jurisdiction around this issue, because it's tricky. One way of avoiding court challenges to this is if the federal government puts out the commission, establishes it as an arm's-length commission, and all levels of government can use the mechanism of administrative interdelegation and give those oversight powers to that body. Then everybody agrees that the body does that, so nobody can go in and say the feds did it on their own and so it's ultra vires over here, or the other way around.

You don't have time now, and we haven't seen the inclination to do this collaboration in advance. We'd hoped for it, but it's not there. However, you could get there by putting the commission in your federal legislation and talking with the provinces and territories, suggesting to do it this way, through administrative interdelegation. It's a technique that's used for cooperative federalism.

• (1930)

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you.

Senator Joyal.

Hon. Serge Joyal (Senator, Quebec (Kennebec), Lib.): First of all, I would like to thank you personally for having provided us with two templates of legislation, which is very helpful. I'm unfortunately a lawyer, and our job here is to draft legislation. When you provide us with advance homework already done, I feel happy.

Mr. Baker, I have gone through your proposal quickly. I recognize it. I had problems with it at first sight, because it doesn't seem to meet what I will call the Carter framework.

The first is your interpretation or definition, if you want, of terms. If you say, for instance, that " 'adult' means a person of the age of majority in the province or territory in which he or she resides", we are dealing here with a charter right, section 7. As a lawyer, I know that a right is a right is a right wherever you are in Canada. When an age is determined, you have that right for that age wherever you are in Canada, so—

Mr. David Baker: I'm not disputing that, but let me just say that definition comes from Carter itself.

Hon. Serge Joyal: Let me finish, sir.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Mr. Baker, would you not interfere, please?

Mr. David Baker: Sure. Of course.

Hon. Serge Joyal: Let me finish, sir. I have my five minutes.

Then you define "assisted suicide", but there's no reference to euthanasia, which is covered by Carter, so there is an omission in your definition.

Then you define the term "grievous", which is a term that we're wrestling with in this committee. You limit that term to "at the end of life". Carter has never said that grievous has to be at the end of life. You limit the concept of grievous to the end of life, while Carter does not include that very specific criterion in its decision.

Later on, on informed consent, you include the test of the reasonable patient and what a reasonable patient would decide in the same circumstances. Carter never imposed that test in its decision.

Then you go on with the test of quality of life, in which the element of personal suffering is not mentioned. It is a key element in Carter. I quote:

...causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition...

It is the person who decides, not the average man placed in the same condition, because the element of subjectivity is important in that decision.

Finally, you judicialize the decision by establishing a review board. Judicializing that decision means that you open any decision to litigation in court.

In my opinion before this committee, venturing in that direction is a very important decision, because it totally changes the relationship with the doctors. How many doctors is immaterial, you know, but you are now in a review board, in a litigation process, and that review board is subject to the surveillance and control of the Supreme Court in Ontario and the Superior Court in Quebec. Therefore, I have some problems with your template. There are good elements in it, but at first sight, in my reading of it, my first objective is to at least satisfy Carter. Then the Parliament of Canada can decide if it wants to increase the rights, because the Charter of Rights represents a limit. Parliament can increase those rights, and we have increased the rights in Parliament on many occasions.

Second, Parliament has the right to decide if a criminal offence is no longer a criminal offence. When Parliament decriminalized homosexuality in 1968, it decided that it was no longer an offence. There are elements in the issue of physician-assisted death that could be decriminalized by Parliament if the will of Parliament is to do so.

That's why I don't think we should approach this issue with the elements of judicialization that would put it below Carter and, in fact, make the decision much more complex for the average Canadian caught up in suffering that is intolerable to an individual who wants to put an end to it because it is grievous or irremediable.

• (1935)

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Senator, you have exceeded the time. I am going to ask if Mr. Baker would be kind enough to respond in writing. The clerks would be prepared to forward the actual questions.

Mr. David Baker: I would do that. May I have just a moment-

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): No, I'm sorry.

He's exceeded his time, so we will move to Mr. Aldag.

Mr. John Aldag: Thank you. I want to continue a bit of the discussion with Professor Downie, and then we'll move on to something else.

We were talking about mental illness as an example. Again, I'm looking at this continuum of floor to ceiling and where we're going along this continuum. I didn't ask specifically, and I don't think you answered, but if we excluded mental illness, would that set us up for a charter challenge or something else?

To expand on that, are there other things? How prescriptive versus limited do we want to be? If we start defining such things as adult or minor and there are other conditions that we include or don't include, does that start us down the path to charter challenges that we may or may not want to go down?

Do you have any comments on that kind of thinking as we move along this continuum?

Prof. Jocelyn Downie: First off, if you're asking whether you could get away with having mental health as an exclusion criterion, I think the answer is no. I think you are absolutely setting yourself up for a charter challenge, and I think you're setting yourself up for a successful charter challenge, because I think you're going to fail on sections 15 and 7.

With respect to how prescriptive to be, there are certain things you should be prescriptive about. I mentioned terms that I think you really need to define so that the provinces don't cut below where you want this to be, or cut below Carter, which they may well do, or leave gaps so that people don't know. One of the things we heard at the provincial-territorial board from a lot of doctors was that they wanted certainty. They said, "Don't have the Carter test of grievous and not tell us anything." We asked them, "What about very serious and severe?" They said, "Yes, thank you, that's fine", because then, for instance, you don't get into a list of conditions.

You want to prevent an erosion of what has been achieved through Carter and the respect of the charter rights that are embedded in Carter. You want to avoid that by being very clear about certain things, but don't get into clinical practice guidelines. You're not into that level of the weeds. That is for the regulators, actually, and I understand that you'll hear from some of them later.

Mr. John Aldag: Thank you.

There's something else I wanted to move into. I'll invite comment both from you, Professor Downie, and from Mr. Baker. It's about the idea in the proposal from Mr. Baker about the review panel. It's one of many elements in the proposed piece we saw.

As I looked at it, I read that there is a composition recommendation suggested, from medical and non-medical up to health care administrators and others. If we start having a judicial review panel, does that start us down the path to inaccessibility, where timeliness may become a factor?

I also wondered about general qualifications. We've heard that physicians already make these complex decisions. I'm wondering whether value is added by bringing in non-medical personnel, a body of 10 people, to try to deal with things that could be the last six months of life or other situations. What's the added value of having that kind of body, as opposed to having other models we've heard of with two physicians, a brief or to-be-determined waiting period, and then a decision made and rendered?

Could I have your comments on the review panel?

• (1940)

Mr. David Baker: Review boards are the mechanism that, on a one- or two-day basis, deal with many issues in the health care field today. That is absolutely established, and it does not result in judicial review morning, noon, and night, sir.

It is a way of flexibly responding to the need for consistency and guidance that comes from the issuance of reasons, and the reasons are what are necessary for true monitoring. The reasons are what do not exist in Belgium and would not exist under the model being proposed, because there are no reasons after the death that are provided beyond the bare bones of ticking the boxes for "grievous", "irremediable", and "intolerable". That is the problem, I would put to you, that requires that a review board be there.

Plus, it puts physicians in the position where they are not being asked to be the judge when most physicians are saying they will not do it, that it's inappropriate and it's unethical. They say they want to provide and will provide information about their patients, the patients they know, whose vulnerabilities they know, whose family situations they know, and for whom potentially they are aware of abuse situations that could contribute to a decision of death. They say, "We do not want a small group of physicians travelling the country and getting paid to administer a lethal dose." They want the person's doctor involved in providing the information that is relevant to the decision.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Mr. Albrecht.

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

I want to thank our witnesses for being here today. I will do my best to leave a little time for you to answer my questions.

I enjoyed reading your brief, Mr. Baker, and Mr. Lemmens, but I found it very troubling. You shared the story of the Belgium experience, and you touched a bit on the Netherlands as well.

I think this paper addresses many of the concerns that many Canadians have in terms of what you refer to, I think very aptly, as "mission creep". It's one concern I have, especially as it relates to what I consider to be some of our most vulnerable Canadians, who are facing mental health challenges and severe depression.

I want to mention some of the quick statistics that you point out in your paper. You said that from 2004 to 2014, demand for physicianassisted dying went from 495 to 2,021. Specifically, even more troubling is the expanded demand for physician-assisted dying from those facing mental health challenges. As I said earlier, I have a special concern for those facing those challenges.

In your paper, on page 10, you say the following: Whether there is no hope for improvement, and thus whether a condition is untreatable or 'irremediable' is particularly hard to assess in the mental health context. The concept of 'refractory' or 'treatment-resistant depression,' for example, is in and of itself highly contested. People suffer indeed tremendously and often chronically from depression. Yet, studies focusing on 'treatmentresistant depression' indicate that many patients, in one study even 60.2%, fully recover.

You go on to say that mental health treatment often takes time, particularly because finding the right diagnosis is often hard and finding the right treatment often harder.

I want this committee to be seized with what I think is an immense responsibility—namely, to be 100% sure, especially in cases of mental health challenges, that we do not offer a permanent solution to what is a temporary problem.

You specifically mentioned in your opening remarks that you disagree with the provincial-territorial recommendations. I'm wondering if you would outline for us some of the specifics on which you disagree so that this committee will avoid the potential pitfalls that could be inherent in adopting that model.

Mr. David Baker: The provincial-territorial report essentially recommends to you that you adopt what is going on in Belgium and the Netherlands, and I think it is incumbent on you to know what is going on in Belgium and the Netherlands. A great deal has happened since Justice Smith received her evidence in that case. Professor Lemmens has given you very detailed information.

With respect to the permanent solution to a temporary problem, I agree with what Professor Downie has said about mental health. It is not open to you, I don't believe, to say that a mental disorder is ruled out under this legislation. However, if you remember, the whole decision in Carter was about whether it was even possible to come up with adequate safeguards to protect the vulnerable.

Have you discussed who we're talking about when we're talking about the vulnerable? I would submit to you that we have offered a definition of vulnerability that, amongst other factors, addresses the issue of temporary depression in response to coming to terms with disability. That is the appropriate way, consistent with Carter, to address issues of mental health. It is not a permanent exclusion from a right to the Carter remedy; it is a statement that while you are vulnerable, the court said you should not receive physician-assisted dying.

That is what the safeguards that you are responsible to enact are to address. The issue of vulnerability has to be discussed. It is not discussed in the provincial-territorial report. It is not addressed whatsoever in Belgium and the Netherlands. That is why there should be a very deep concern.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Senator Cowan.

• (1945)

Hon. James S. Cowan (Senator, Nova Scotia, Lib.): Thank you.

Professor Downie, you've had an opportunity to review the provisions of the draft bill as prepared and circulated by Mr. Baker and Mr. Sharpe. Can you advise us of your views on whether it's meeting the test set forth in Carter and on its compliance with the provisions of the Charter of Rights and Freedoms?

Prof. Jocelyn Downie: I think it is not Carter compliant. As a couple of examples, it doesn't include euthanasia, which is clearly in Carter, and it doesn't include terminal illness, which is not precluded by Carter.

It's not charter compliant. Think about the disclosure of personal information about a patient to their family without their consent. That's a privacy violation.

It's not consistent on autonomy. You have 45 days. You have to schedule 10 people together. You have an oral hearing, which can be triggered by a third party who has nothing to do with the case. You have to bring a very sick, suffering person in front of the oral hearing. I think that's absolutely contrary to Morgentaler. A 10-person panel and 45 days is nothing like what got struck down in Morgentaler.

It's not division-of-powers compliant either, because it tells the public trustee to do certain things, and the federal government does not have the power to tell provincial-territorial public trustees what to do.

Finally, I think it's profoundly stigmatizing to put physicianassisted death in the section of the Criminal Code headed mental disorders and to conflate people who are seeking medically assisted death with people who have been accused or convicted of a crime and who have been found to be so severely mentally incapacitated that they are not criminally responsible. That's what's at the heart of this piece of legislation, and I find that deeply troubling.

Hon. James S. Cowan: Could you share with us your views of the Belgian experience that Professor Lemmens spoke about, and your own impressions and knowledge of that?

Prof. Jocelyn Downie: I think we have to be very careful about evidence. It is important to note that much of what troubled you in that report was put in front of the court in Carter. It was tested. The experts from those countries were brought in and cross-examined, and Justice Smith did not find them to be compelling. She said that those regimes work, that we can say the risks can be managed in those regimes, and those regimes don't have pre-authorization.

The second thing is that while Carter at trial was quite a while ago now, the crown introduced new evidence at the Supreme Court of Canada, which is actually quite unusual. They had fresh evidence in the form of an affidavit from Professor Montero, including much of the evidence that's in that memo. The court said it wasn't persuaded that anything was changed by that and that you must be very careful about anecdotal evidence. That is because anecdotal evidence is presented as what the people in the street are saying, which is really important. However, I probably don't have to tell this group in particular that what the people in the street are saying is not necessarily reliable.

What you have to rely on, I think, in relation to the Belgian data, is the evidence that was tested in court and the empirical evidence from the actual researchers. In Carter and at the Supreme Court level, it was presented and it was updated.

Unknown: If I could—

• (1950)

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Do not interrupt. The senator has the question, the professor is answering, and the senator will determine who responds.

Hon. James S. Cowan: Thank you, Chair.

There have been some suggestions that we should be very careful how far we go, that we should just stick very carefully to the federal thing and leave everything else to the provinces. What's your view of that, having participated in the provincial-territorial panel? Is there a sense of that being the way to go, or is there a sense that the provinces and territories are looking for overall framework leadership from the federal Parliament?

Prof. Jocelyn Downie: The provinces and territories have said they want a harmonized approach. They, I think, went ahead with that panel because of what's going on federally. They knew there was going to be a gap in February, so they responsibly said, "We need to deal with this." That panel said, "We have to take a broad view, because we don't know if there will be anything federal, and we can't have a gap."

That's why it's broad. It directs certain things at the federal government in cases where it is clear that those couldn't even be under provincial and territorial jurisdiction, but make no mistake that there isn't a sense that some of the things that are directed at the provincial-territorial governments in that report could not be done by the federal government. They're targeted at the provincial-territorial governments because it was a provincial-territorial panel, but there are a number of issues over which there's overlapping jurisdiction. The report directs those to the provincial-territorial government, but those issues could just as well come over to the federal government.

For now, I would say, take all of them. Take what is clearly and only federal, and take that which is joint, because you need to do that in order to prevent inconsistencies and gaps and because you have a mechanism to avoid appearing to ride roughshod over, in particular, Quebec and the others because you can have a substantial equivalency clause.

The Joint Chair (Hon. Kelvin Kenneth Ogilvie): Thank you. That completes our testimony this evening. We thank the witnesses for being here and we thank the panel for the questions.

We will temporarily suspend for a very brief time, and then we are going into an in camera session. Those who need to leave need to do so quickly.

Thank you very much. We are temporarily suspended.

[Proceedings continue in camera]

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