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Chair

Mr. Bill Casey

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• (0850)

[English]

The Chair (Mr. Bill Casey (Cumberland—Colchester, Lib.)): I call the meeting to order. We have quorum and we'll welcome our guests, Rob and Rob.

We look forward to your presentations. We have quite an aggressive agenda today to try to get through the witnesses and then clause-by-clause consideration. I've suggested to the witnesses that the shorter their presentation, the more questions we have to ask.

I have another matter. I'm seeking unanimous consent to see if we can just go to one round of questions. Does everybody agree to that in the interests of getting through this issue? Do I have unanimous consent to go to one round of questions?

Okay, one round of questions it is. We'll have one round of seven minutes.

We'll start with one of the witnesses, the Honourable Rob Nicholson.

Hon. Rob Nicholson (Niagara Falls, CPC): Mr. Chair, vice-chairs, and members of the committee, it's an honour to be here today to present my private member's bill, along with my fellow colleague, the member for Don Valley West, Mr. Rob Oliphant.

Bill C-233, is an act respecting a national strategy for Alzheimer's disease and other dementias. This bill calls upon parliamentarians to enact legislation for a national coordinated strategy for what has been termed Canada's invisible killer. Alzheimer's and dementia are major health problems that transcend partisanship and are affecting a staggering number of Canadians currently. I believe you have heard that 740,000 Canadians currently suffer from Alzheimer's, and ever more concerning is the fact that this number is expected to double in the next 20 years.

This is why I believe Canada needs to have a plan. I'm certain Mr. Oliphant will touch upon his experiences with Alzheimer's and dementia when he speaks, so I would like to take a moment to note the work on this topic by a former member of Parliament, Claude Gravelle. It's most heartening to know that in matters of concern to Canadians and their families, MPs can work together across party lines to unite and advocate for research, collaboration, and partnership, to find cures, timely diagnoses, and other support for treatment. This co-operation will lead to positive outcomes for Canadians who suffer from Alzheimer's and dementia, and will reassure their loved ones that people who are suffering from this will have the proper care. Canadians expect that their parliamentarians will work on their behalf to resolve these critical issues.

The impact on families whose loved ones are suffering from Alzheimer's or dementia is extensive. Three out of four Canadians know someone living with dementia. I can't tell you how many people have approached me over the last couple of months to tell me the stories they have experienced within their families. This not only takes an emotional, psychological, and physical toll on those who are providing support for loved ones, but it also has a severe financial effect.

In 2011, caregivers provided 444 million hours of care, representing \$11 billion in lost income, and about 230,000 full-time jobs. By 2040, caregivers will be providing 1.2 billion hours of care, over two and a half times the number of hours they provide today.

Alzheimer's and dementia are no respecters of people as they rob them of their dignity, independence, memory, and time. They know no bounds and are not restricted to social or economic factors. No one is immune to these terrible diseases and the suffering that follows.

It brings to mind the late United States President Ronald Reagan. The former leader of one of the most powerful and wealthy nations on earth could not be safeguarded from the ravages of Alzheimer's. On November 5, 1994, I remember him as the 40th president of the United States, addressing the American people by writing, in part, "I now begin the journey that will lead me into the sunset of my life." That journey took 10 slow and painful years. His loving wife Nancy referred to it as the long goodbye.

Far too many Canadians endure the long goodbye. My own father, who I cherished, passed away from complications due to Alzheimer's, and I am joined by many who have dealt with or are dealing with a loved one suffering from one of the various forms of Alzheimer's and dementia. Again, we know that this is going to increase.

The bill I have put before you, first of all, proposes to establish a round table to receive input from all Canadians. It would develop a national strategy, while ensuring the autonomy of the provinces remains intact. Second, it would encourage greater investment in all areas related to Alzheimer's and dementia, in addition to coordinating with international bodies to fight against the disease. Third, it would seek the assistance of the provinces in developing and disseminating diagnostic and treatment guidelines based on new research. All of these measures have been thoroughly considered to ensure the successful passage of this legislation.

Importantly, please note that this bill does not restrict timelines or financial criteria. This is a deliberate intention to remove potential barriers, such as the need for a royal recommendation. Simply put, this bill is crafted for implementation, achievement of deliverables and, ultimately, resilience at third reading. The objective is to enact legislation that would provide solutions to assist those who suffer from Alzheimer's and dementia, and to aid family members and caregivers.

The World Dementia Council was created by the G8 in 2013 as a global coordinating movement against Alzheimer's and other dementias. It's trying to harmonize those efforts and bring together global know-how.

Canada, along with its G8 partners, had convened a meeting in London, England, in December 2013. The sole purpose of that meeting was to provide a structure for a worldwide response to this crisis. It was the first time that the G8 countries had gathered together to address a health care issue. It's clear that Canada has already agreed to work with our partners to address Alzheimer's.

In order to fulfill this mandate, we have to develop similar programs here at home. Bill C-233 would help achieve this outcome through the national strategy. I would reiterate that Bill C-233 would respect the health care accountability of each province. I was very careful in the drafting of this bill to ensure that it does not require a royal recommendation.

I would be remiss if I didn't acknowledge and thank the Alzheimer Society of Canada for their unwavering support of this bill. Their mandate and the objective of this bill closely align and support one another. The Alzheimer Society stated that it was pleased to see political parties working together to address dementia. It urged all members of Parliament to get behind this bill, suggesting that a national strategy focusing on research, prevention, and improved care is the only solution to tackling the impact of this disease.

I believe that support for this bill is the right thing. Alzheimer's and other dementias are major health issues that impact hundreds of thousands of Canadians, and it is a problem that is growing every day. Canada needs a strategy now, so Canadians can be prepared to take on this health crisis in the future.

Thank you for your support.

I'd like to now turn it over to my colleague, Robert Oliphant.

• (0855)

The Chair: Thank you very much.

Mr. Oliphant, you have the floor.

Mr. Robert Oliphant (Don Valley West, Lib.): Thank you, Chair, and thank you, committee members.

I'm hoping that today you will experience and see what I believe is the best way legislation should be crafted and taken through the House of Commons, in this collaborative effort.

I want to thank my colleague. One of the things about this new Parliament—and I think that there should be, and it's gradually starting to be—is a collaborative way of working together. Working with the member for Niagara Falls, Mr. Nicholson, has been a great treat. He is a senior member, a former minister, who knows the way

things actually work, and who makes me look good. I want to thank him.

Hon. Rob Nicholson: Make sure that's part of the record.

Voices: Oh, oh!

Mr. Robert Oliphant: You, as members of this committee, have the chance to do the same thing we are modelling for you today, which is to work collaboratively to get a bill passed that has its roots in the New Democratic Party with Mr. Gravelle and is continuing now with the other two parties in the House. I think this committee has a chance to make history by having the first national disease strategy adopted by Parliament. We are not unaware that it could become a model for other diseases and that there is a hunger for the federal government to play a leadership role—not encroaching upon any provincial powers to actually do the delivery of health care—by providing an operation of collaboration, co-operation, and best practices.

I want to begin by telling you the story of Ewart Angus. Ewart Angus was a member of the church where I was a minister for many years in Toronto. Ewart died, however, before I became the minister, and he left a sizable amount of money to the United Church of Canada. The United Church of Canada sort of lost track of that money and allowed it to grow over many years. I discovered it in the late 1990s. It had reached \$5 million, and it was earmarked for seniors care in north Toronto. Nobody knew what to do with it. I did.

Ewart had been a member of our congregation and we asked for the money to be transferred to that congregation to enact its vision of providing care for people with Alzheimer's and other dementias. We built Angus House on Merton Street in Toronto, a really amazing model for Alzheimer's care. It has three floors of market and subsidized rent apartments geared towards seniors, and two floors for Alzheimer's care. This means that if one member of a couple has dementia, one of them can stay in their home while their spouse goes to a secure floor with good medical care. This was originally intended for early Alzheimer's, mild stage, but has now progressed to medium-stage and even more advanced-stage Alzheimer's.

Being good fiscal conservatives, as I am sometimes, we actually ended up with \$2 million left over at the end of that project after having built the building, so we built another one called Cedarhurst, which is in Don Valley West, coincidentally. It provides another setting of 26 rooms for long-term residential care for people living with dementia.

It's based on a model in Australia, which we as a congregation came across, of relational care that was developed by Dr. John Tooth. Small groups of people with dementia, five at a time with one personal support worker, live in a residential setting and gradually develop a community that honours the person. It continues to this day. I was at Ewart Angus Homes' second campus, Cedarhurst, last week, and they are continuing to evolve and develop.

We need a national strategy because that model of care of purpose-built, intentional housing for people with dementia and long-term care needs is unfortunately almost unique in Canada. It links with Sunnybrook Health Sciences Centre, the University of Waterloo, and a variety of satellites. However, it is quite limited.

Mr. Nicholson's bill offers the possibility of taking best practices from a place like Ewart Angus Homes and spreading them across the country. It does that by capturing the attention of the Minister of Health and requiring her—or him in the future—to submit an annual report to Parliament. It fosters co-operation and collaboration through an advisory council, and it demands an updating to Canadians on how we're doing. It encourages increased funding for research, clinical care, patient support, and family support. It does that in the way that the federal government alone can do it, through the powers of convening, the powers of organizing, the powers of displaying exemplary forms of care, and by ensuring that we're able to spread that across the country.

There may be gems of care I don't know about in Winnipeg, Vancouver, or Cape Breton Island. I don't know where those models of care are.

• (0900)

By having a collaborative approach, we will learn where those things are and be sure that we have that kind of co-operation, and also bring in international best practices. I think the bill is quite clever. It's clever in that it draws attention to the issue. It requires the government to pay attention and report back to Canadians. It fosters collaboration, through an advisory group, and it begins to put some accountability on the government, as Canadians are looking for it for this particular disease.

I'm sure you've had drawn to your attention the report that was issued on November 15, 2016, "Dementia in Canada", by a Senate committee, which is co-chaired by my good friend and colleague Kenneth Ogilvie, and Senator Art Eggleton. It's a very fine study on dementia. It calls for a collaborative approach, what they're calling a Canadian partnership, to address dementia. By having an advisory committee embedded in this legislation, we would actually be able to live out what the Senate—after a very thorough study, much more thorough than we've done in the House of Commons—would actually envision. I commend it to your attention and to take great care as you go through clause-by-clause study on the bill, that we don't lose the spirit of what the Senate has learned, that Canadians are looking for leadership. We can provide that leadership by having such an advisory council bringing together the best of clinical treatment and research, as well as social workers and family caregivers, and those living with dementia.

I'm going to close by talking about an event I was at last week. The Alzheimer Society of Toronto, a formidable force under the umbrella of the Alzheimer Society of Canada, and the Alzheimer Society of Ontario, had a fundraiser. It was an amazingly successful fundraiser with really the best dinner I've had at a fundraiser in my life, but that's an aside. At that event, a woman with Alzheimer's made the keynote speech. She carefully and cautiously chose her words and moved me to tears, as a person who is aware of her circumstances and is looking at what my former colleague Marian Ritchie called the long journey home. She gave me the courage and

empowered me to keep fighting this fight. I'm encouraging you to do the same to make sure that we show Canadians that this Parliament takes this disease seriously and that we take every step we can to make sure that we engage with those who know more than we do and make a difference in the world of Alzheimer's and other dementias.

Thank you.

The Chair: Thank you very much. I appreciate your comments.

Ms. Harder, earlier we moved a motion with unanimous consent to just reduce it to one series of questions. We're not trying to prevent anybody from having an opinion or anything, but today is our only chance to voice our opinion on this bill. If we don't complete the bill today, it will go back to Parliament without amendment or comment. I'm not trying to rush anybody, but I just want to make sure that we have a chance to have our voices heard. I do sense a consensus on it.

We're going to start our question period now. There will be seven-minute rounds of questions.

We'll start with Ms. Sidhu. I understand you're splitting your time with Mr. Oliver.

• (0905)

Ms. Sonia Sidhu (Brampton South, Lib.): Yes, Mr. Chair.

First, I want to thank you for coming together to put forward this bill. We heard some very powerful testimony at the last meeting on this topic. I want to highlight all of the caregivers, particularly the challenges they face with the wait times for getting PSWs and other support workers. I met with the Canadian Nurses Association the other day and we discussed this matter.

Can you talk about how you view the issue of support workers and family members who need to take time off to support their ailing parents or dependants, as reflected within this bill and the future strategy?

Hon. Rob Nicholson: Let me start off.

I'm supportive of any measures that change the Income Tax Act, quite frankly, in terms of giving credit to people who take time off to look after family members. There have been steps in that direction, and I'd certainly welcome anything further, because these things do take a great toll on families. That's one of the things that has impressed me. In fact, one of the witnesses you had here, I believe yesterday, Tanya Levesque, talked about how much time she has had to devote. What happens is that it becomes, quite frankly, a full-time job for the people who are the spouses of the individuals who are suffering from this. They need care all the time. I set out in my opening remarks the amount of time it takes health care workers when people end up in these facilities.

I'm hoping, and it's a sincere hope, that some day we will solve this, that we will get a cure for Alzheimer's, that we can do this, but it's not going to be done unless there is coordinated research into this. I'm hoping that a bill such as this would help that interchange, that exchange of information.

My colleague Mr. Oliphant spoke about the model they've instituted in his area of Toronto with respect to the treatment of people. This is exactly the kind of information we want to share. I believe that bringing together an advisory council as set out in this bill would be a step in that direction.

Thank you.

Mr. Robert Oliphant: I might just add that the advisory council could look at other issues. Much of what you say is really within provincial jurisdiction and the delivery of health care. This body, however, could look at things that are in the federal realm to ease that burden on families and caregivers.

I should mention that, at Ewart Angus Homes, the monthly charge for someone living in that home on Merton Street is in the \$2,000 range. I think it's about \$2,400 a month right now, between \$2,000 and \$3,000 a month. At Cedarhurst it's \$7,000 a month. They're both not-for-profits, but because we have no provincial subsidy for the one home that we have for the other, that's how much it costs. We have to look at ways to find support.

People will be living at home. They need home care. They need all those things, which every disease group needs. I think this is a way to draw attention to those needs in a profound way, which will have spillover effects into other diseases as well.

The Chair: Ms. Sidhu, your time is done.

Now it's Mr. Oliver for the last half.

Mr. John Oliver (Oakville, Lib.): Thank you very much for the bill. I think all of us know and have family members who are experiencing dementia, so it's a very important piece to come.

My question goes to the concept of it being a model for other diseases and the clause that deals with the establishment of the advisory board. I'm picturing a world where the minister is trying to run 15 to 20 advisory boards and how they would live with that and manage that kind of environment. Do you have any thoughts or comments on this, on what might be the criteria for when an advisory board would be established?

Another thought I have is on the time-limited nature of it. It's three years, with potential renewal. If we have just a three-year term and then sunset them, it might be easier. That's where I'm looking for advice on this: how do we manage multiple advisory boards?

• (0910)

Hon. Rob Nicholson: One of the things about this is that it does not take up all the time, efforts or resources of the health minister. We're not demanding that of the minister. I know the ministers of health, whether provincial or federal, have a huge number of things. It's set out in a way where the committee is brought together a couple of times a year, and then with a clause to revisit the whole idea.

When I thought about this area of Alzheimer's and had the opportunity to look at it, I saw there was a gap in this area. It's something where, even 30 years ago, if you started talking about this, I don't know how aware I was, or anybody was, of these things. This has grown exponentially. I read in the last number of months, prior to introducing this bill, that this thing is going to be doubling. With the aging population in Canada, age is one of the criteria that you would look at, but quite frankly, it's independent of aging. We all

know people who, in their forties or fifties, have Alzheimer's. I thought it would be good that we focus on this particular disease. Again, if you look at it carefully, it's not taking up all the minister's time. I think it's well worth the resources and the time.

Mr. Oliphant.

Mr. Robert Oliphant: I would add that I think this is one of the most economical ways for a government to work efficiently. This actually serves a minister well. I don't think there is any minister who wouldn't be well served by having good advice. That good advice is unpaid. It is a meeting once or twice a year of experts. I think getting that kind of expert advice into a ministry, into the Department of Health, into the Public Health Agency of Canada, is a superb and very economical way of doing it, far more so than hiring consultants.

One of the realities is that governments hire consultants all the time. I think this is a much more effective, organic, and community-based way of getting that information into a minister's head and heart.

Mr. John Oliver: I have one quick last question.

The focus is on a national dementia strategy. There's a weighting in the bill to Alzheimer's, and, as you know, there are multiple causes. Alzheimer's is the main cause, but there's Huntington's, Parkinson's, and vascular dementia.

Would you have a reaction if we focused this on dementia versus Alzheimer's and dementia and—

Hon. Rob Nicholson: Dementia is included, but the focus of the bill is Alzheimer's. That's the bill, because, again, from what I have read on this—and I've experienced it for quite a number of years, and I've done quite a bit of research in the last six months or so—it seems to me this is something we could someday be able to cure to really make a difference. I'd like the focus to be on Alzheimer's, but of course there are other dementias, and this is a component of that. Those are my thoughts on it.

Thank you, Mr. Chair.

Mr. Robert Oliphant: I understand there are amendments coming in.

I understand taking a named society out of the bill. I get that, because those are temporal, and you want a bill that is bigger.

I think it's important to focus, as the Senate has, on dementia. I get that. I think taking any mention of Alzheimer's out is problematic politically, as well. I think there is a way to shape that phrasing that at least preserves Alzheimer's in the bill in some way, while understanding, as the Senate did, that dementia is quite broad.

I would hope that any kind of expunging of Alzheimer's all the way through doesn't happen and that there's a clever way to ensure that we keep that word in there. I argue partly out of a personal story. I have seen in my own life how Alzheimer's is what people first think, and it can actually do a disservice to people with other dementias, so I understand the reason to focus on dementia. I would just try to hold some concept of Alzheimer's in this bill.

The Chair: Mr. Webber.

Mr. Len Webber (Calgary Confederation, CPC): Mr. Chair, I'd like to share my time with the honourable Ms. Harder, please.

First of all, I have to applaud you, Mr. Nicholson, for your work on this bill. It's a fantastic bill. I applaud you too, Mr. Oliphant, for supporting the bill.

I think it's something that has to be done. My grandfather had Parkinson's as well, and I know how hard it was for him to go through nine long years in long-term care.

I know both of you have likely seen the proposed amendments to this bill. I assume you have. Mr. Oliphant, you just talked a little about one portion of it.

I'd like to know Mr. Nicholson's thoughts on the proposed amendments and perhaps he will share with us any concern he has there. Likewise, Mr. Oliphant, could you share your thoughts on the proposed amendments to this bill?

• (0915)

Hon. Rob Nicholson: Mr. Webber, thank you for your interest in this.

This bill was unanimously supported by Parliament at second reading. As you know, that's when bills are substantially supported or not supported. I was very grateful at the time that this received the support of every single member of the House of Commons. That's what you're dealing with here, number one.

My intention was to focus this on Alzheimer's because of my belief that someday we will get a cure for this, but there should be a coordination between all those who want to do something about this disease and want to find a cure and for all those who want to care for people who are suffering from disease.

My colleague Mr. Oliphant made a very good point. If there are good practices somewhere, then let's share those.

I remember when I was a regional councillor. When we had seniors homes in the region of Niagara, they kept learning from the previous ones that were built, and they shared information. It was fascinating and heartwarming for me to see that, as each one got built in Niagara, they kept building on what they had learned or what they had heard on the best way to treat.

To the extent that we do anything to coordinate that and bring together these good ideas, we are further ahead on this. I don't want this to get lost by including all diseases. Do you know what I mean? I'd like to solve all health diseases; everyone would. But I like the focus, and I believe the focus of the bill, as it was passed by Parliament at second reading, is on Alzheimer's and other dementias.

Mr. Robert Oliphant: I agree. I guess if I'm going to go to the wall, it's for that advisory committee. That would be my number one concern on this bill, because I know the way things get lost in bureaucracies and ministers suffer from the worst disease, which is called bureaucratic capture.

What the advisory committee does is it ensures there is a living, constant community of advice coming from people on the ground. At a federal level, that can get lost very easily. It's a little easier to keep that at a local level or at a provincial level. At the federal level,

to keep this real and away from getting into bureaucratise, I think we need that kind of a committee. It's a very light committee, and it's not onerous. I think ministers could benefit from that.

In terms of Alzheimer's and other forms of dementia, as I said, I would like that name in there somewhere. I don't want to lose it completely. I understand broadening it, because of Parkinson's, vascular and other forms of dementia. I get that as well. I've even noticed that Ewart Angus Homes had to develop and move from Alzheimer's, to Alzheimer's and other dementias, to dementia and Alzheimer's. It's the way the world is.

Mr. Len Webber: Thank you.

How much more time do we have?

The Chair: You have two minutes and 49 seconds.

Mr. Len Webber: Just a very quick answer to this. You talked about the G8 conference on Alzheimer's back in 2013. What are other jurisdictions doing? Are they way ahead of us, Mr. Nicholson, with regard to—

Hon. Rob Nicholson: It's hard to say. In an effort to shorten my comments, I didn't get into all that.

I think there is a greater awareness. It's not just the G8. I think I mentioned the United Nations, in terms of kind of coordinating this information. It's a greater realization of the globalization of this world that we have to share this information, that we are not alone on any of these issues here. If you go back 50 or 70 years, research was done exclusively and it wasn't shared. There's a greater realization today, and I think it's a step in the right direction that we share information. Again, it's a function of the globalization of the world. It's what we have to do. It benefits all of us.

Ms. Rachael Harder (Lethbridge, CPC): I think this is what I'm hearing you say, and I simply want to make sure. With regard to the language, using Alzheimer's versus forms of dementia in general, if we were to put a focus on Alzheimer's, it could mean we would find a cure. The probability of that is quite high, based on the research that's taking place in Canada, and could further take place with greater funding and expertise on this matter, and in partnership with other countries. Whereas if we were going to take that same chunk of money and spread it over, let's say, 10 different dementias, it wouldn't go nearly as far and it wouldn't produce a cure.

Am I understanding you correctly on this?

• (0920)

Hon. Rob Nicholson: I'm hoping... We want to solve all these different issues, but I've come to the conclusion that if it is one of the focuses of governments and government coordination and internationally on Alzheimer's, we can and will make a substantial difference with respect to this particular disease. Those are my thoughts on it.

Ms. Rachael Harder: The last thing I would ask you then is, do you have any stats? If we look at the whole spectrum of dementias, is Alzheimer's the one that the greatest percentage of the population suffers from?

Hon. Rob Nicholson: I would say it is.

Mr. Robert Oliphant: What I've read is it's about half. About half of dementia is Alzheimer's and the other half is the collection of a variety of ones. It's tough, though, when you look at a family. If the focus is on research, absolutely there's some really important stuff happening there. A family's life is really more than disrupted, it's overturned by any of those dementias.

My problem is, as a pastor dealing with families—and I'm the bleeding heart at this table—I want to help them all. I've just seen too many families where they simply don't know where to turn. I am looking for federal government leadership in that way. It'll be up to you to decide how much you want to focus on precision and how much you want to broaden that mandate. It'll be up to you.

Ms. Rachael Harder: Thank you.

The Chair: Thanks very much.

Ms. Blaney, welcome to the committee. You have seven minutes.

Ms. Rachel Blaney (North Island—Powell River, NDP): Thank you, and thank you to our witnesses today.

I spent many years volunteering for an organization that provided respite. A large number of the families that I worked with were dealing with dementia. I would either support the person with dementia or support the family in different ways. I have a great amount of compassion for the significant impacts this has on communities and the families.

My first question is going to you, Mr. Nicholson. You mentioned thanks earlier to Claude Gravelle, who introduced Bill C-356, a national strategy for dementia. Unfortunately, that bill was defeated. It was a very close vote: 140 said no; 139 said yes. The majority of the Conservative MPs, including you, did not vote positively for this bill.

Given how similar your legislation is to the last bill, why did you choose to narrow its focus?

Hon. Rob Nicholson: I thought about this, as I say, about six months ago, and I remembered the bill because.... I started reading about the problems with Alzheimer's and indeed other dementias while I experienced this in my own family. When I looked at it, I thought the bill we had before Parliament would have required a royal recommendation. That was what we heard at the time. That means it wouldn't have gone forward.

The other problem with it was in regard to the timelines. If you'll notice, in mine I made it that the minister will convene a meeting within a 180 days, within six months, basically. I thought that was more realistic than a statute requiring the minister to move on this thing in several weeks. I didn't think that was realistic. Plus the feedback that I received at the time was that a royal recommendation would be needed; therefore, it wasn't going to proceed.

That being said, when I thought about it, I thought okay, if we can modify it, modify those challenges, then I believe the bill should be able to go forward. My colleague Mr. Oliphant will confirm this. At the time I spoke with him about this, he analyzed the bill just on those counts alone. As it comes before you today, I don't think you've heard anybody say or had any advice that it will need a royal recommendation, because we tried to be very careful. I believe the timelines are very realistic.

At the same time, the overall concept of getting into this area, on every occasion, I have mentioned Mr. Gravelle. When I have spoken to people privately, who, as you can probably imagine, have engaged me on this, I have pointed out that this is not the first time Parliament has had a look at this. I hope that it goes forward.

Again, I asked a colleague from another political party to second this bill here. I do want it to be accepted by everyone.

Those are my comments.

● (0925)

Ms. Rachel Blaney: Mr. Nicholson, if you're concerned that the legislated remuneration requirement would act as a barrier to this bill's or the past bill's passage, why is it necessary that in your bill you actually explicitly forbid any form of remuneration?

Hon. Rob Nicholson: I didn't want to have anything on which the argument could be made. You know what happens on these things. People will make the argument that this is going to require money from the government, that the government is going to have to spend money. I tried to be as careful as possible, because I know there are people across this country who are prepared. You meet them all.

You talked about yourself and your contributions. I've met many people like you in my own constituency of Niagara Falls, Niagara-on-the-Lake, and Fort Erie who just contribute their time. They're volunteers. They're not in it to be paid. I believe that there are experts who would come together for this.

By putting that in there I hope to avoid the argument that this would need a royal recommendation, because I didn't want to have any technical reason for why something like this would not go ahead.

Those are my reasons.

Mr. Robert Oliphant: I would like to add to that.

Back in 2011 the people spoke and sent me home from this place, and they brought me back in 2015. Between 2011 and 2015, I was president and CEO of a national health charity for people with asthma—another “A”. The way we would focus as a health charity is that we would prefer not to have remuneration at a government advisory board, because that is part of our job as a society. We would like expenses paid for going to meetings.

However, to maintain our independence, to maintain our integrity as a not-for-profit and charitable organization, and we were both a patient organization as well as a health charity, we would think it's actually appropriate for us to work in that charitable sector advising government. That doesn't mean we don't want government funding for various projects. We were always looking for PHAC, Public Health Agency of Canada, funding, etc.

However, I would say that part of the bill is not a negative; it is a positive in the health charity world. It's the way we work. It's the way we keep our independence, the way we do it.

In terms of caregivers and patients going to those meetings, again, we think expenses, obviously...and that's the way meetings happen; there's a budget for a meeting. But remuneration in terms of a per diem payment for your expertise would not be appropriate.

Ms. Rachel Blaney: When I talk about remuneration, refunding expenses is part of what we're talking about. One of the challenges, because this is very clear, and nothing that's in the legislation.... I also ran a charity for eight years, and one of the challenges that I feel could come to this bill is that we're losing people. We saw the witnesses who were here earlier this week, and they were people who are working very hard, especially when you think about direct caregivers. We heard about the direct caregiver and how financially significant the impacts were. If we offer absolutely nothing, it potentially cuts off some groups of people.

Mr. Robert Oliphant: I disagree that nobody would receive remuneration for the performance of their duties. In my mind that very much is payment for expertise. Absolutely, if you're having an advisory committee meeting, you would follow Treasury Board rules, etc., that would work into current departmental budgets.

Ms. Rachel Blaney: I look forward to seeing that happen.

Mr. Robert Oliphant: There was never an intention to not refund expenses for meetings that should be paid.

Ms. Rachel Blaney: Then I think it should be removed from the legislation.

I want to get on to another issue. Unlike Bill C-356, the national strategy for dementia act, this legislation doesn't contain any provisions to augment the capabilities of the voluntary sector. Can you explain why you chose to exclude any mention of the voluntary sector from Bill C-233?

Hon. Rob Nicholson: The voluntary sector is an inherent part of what this is all about: people who volunteer. We are trying to bring together people who have expertise, and their expertise could be in many ways. We try to be as inclusive as possible with respect to the legislation to bring together this advisory board, and this is a step in the right direction.

• (0930)

Mr. Robert Oliphant: It's there, the lay advocacy sector.

Hon. Rob Nicholson: Yes, it's there, so it is not restrictive, and indeed the volunteer sector is huge in all aspects of looking after people who suffer from diseases such as this. Again, I use the word "remuneration" specifically, which is—and this is the lawyer in me—the payment for expertise. The expenses of getting to the meeting here, or the hotel over there, are not included in this.

The Chair: Mr. Kang, you're next.

Mr. Darshan Singh Kang (Calgary Skyview, Lib.): Thank you, gentlemen, for bringing this bill forward.

As we discussed before, almost everybody is affected by some kind of mental disease in their family or friends. This is a good bill, and of course you're going to have my support.

At the first meeting on Bill C-233, on November 17, Mimi Lowi-Young—

Mr. Len Webber: Mr. Chair, I understood that we were going to go through seven minutes for each party and then we would end the questioning at that time.

The Chair: We're going to do the first seven-minute round of questions, so it's Liberal, Conservative, New Democrats, and Liberal.

Mr. Len Webber: It's Liberal again, okay. You made it sound like seven minutes each and then we would end it there, but I guess I misunderstood.

The Chair: It was just for the first round.

You may continue, Mr. Kang.

Mr. Darshan Singh Kang: Thank you, Mr. Chair.

I'll start again. At the first meeting on Bill C-233 on November 17, Mimi Lowi-Young, former CEO of the Alzheimer Society of Canada, told the committee that women are most affected by the disease, that 65% have the disease and 72% are primary caregivers. Do you anticipate that a gender-based analysis plus assessment will form part of the discussion leading to establishing a national strategy on Alzheimer's disease and other forms of dementia?

Mr. Robert Oliphant: It's an excellent point and that gives me a chance also to commend Mimi on her fine work while she was the CEO of the Alzheimer Society.

Her point is well taken, that there are certain diseases that disproportionately affect women, and this is one of them. Dementia does disproportionately affect women. In terms of the gender-based analysis we believe has been done—two guys sitting down here, frankly—we're looking at this disease to recognize that diseases that have affected women have historically had less attention, less funding, less research, than diseases that have affected men if you look at the funding that has gone on, and we're trying to change that.

I don't think that we have a focus on women in this bill, but because we're looking at dementia, it will focus itself on women and men. Since women have that caregiver facility, I think that looking at other things from the federal perspective that could affect this, whether it's changes to EI or episodic respite care and those kinds of things, those kinds of things could be discussed because there is a federal mandate there. I think this is an important statement that we need to put attention on diseases that have disproportionately affected women.

Mr. Darshan Singh Kang: Thank you, sir.

The bill acknowledges the role of caregivers for individuals living with Alzheimer's disease. Can you talk a little bit about home care? Will home care be partially playing a role in that, or will the main focus be on home care? I'm a fan of home care because personally, home care has helped me and my family. I think home care could help everybody if there were proper home care in place. That's my second question.

• (0935)

Mr. Robert Oliphant: This bill won't directly impact on long-term care or home care or on the various things that need to go into that national health accord. It would focus instead on the disease that could lead to requirements for it, but I think, obviously, I would encourage this committee to be taking up some of those issues.

This bill, I would say, only indirectly would affect it, but an advisory committee could remind the minister about other responsibilities that he or she would have and so it could fit in.

Hon. Rob Nicholson: I'll give you the example of the tax credit for people who look after people. This is another issue and it's good that you raise it, because this is a huge component of it. The individual who acquires this disease suffers, but everyone around him or her suffers as well.

Mr. Darshan Singh Kang: We can have all kinds of advisory boards in place and if there's no back-up plan in place I think it's defeating the purpose of doing all this.

Mr. Chair, I'll share my time with Mr. Oliver.

Mr. John Oliver: Thank you very much.

I want to come back one more time to the intent of the bill. I'm sorry to be focused on this.

We heard from Dale Goldhawk, the vice-chair of Alzheimer's Disease International, and from David Henderson, Canadian Society of Palliative Care Physicians. We heard from Kathleen Jamieson and Sheila Pither, Council of Senior Citizens' Organizations of B.C. We heard from Mimi Lowi-Young and others. They all spoke to the need for a national dementia strategy. They all want a cure for Alzheimer's, but they spoke to the need for a national dementia strategy.

I'm concerned that there are two agendas in this bill. There is the drive for the cure for Alzheimer's, but at the same time there's a need to have a national strategy on how we help people and caregivers living with dementia continue.

One last time—and maybe I'll start with you, Mr. Oliphant, and then Mr. Nicholson—I'll ask you what your views are on separating these out a bit more.

Mr. Robert Oliphant: It's one of those cases where everything is good. I think this week when I read the Senate report on dementia I recognized that the bill needed to have that. I think it does have it in it and it has drawn attention to Alzheimer's and other dementias.

My overall concern is people and people with dementia regardless of where it comes from. That's my first thing. However, I recognize that Alzheimer's is a focused area of research that needs attention. I just don't want to lose it completely, because I think that there is huge promise in that, whether it's at the Baycrest Health Sciences centre or others where they're doing that kind of focused research.

My hope is that it doesn't get lost in the whole mix, but the reality is dementia is a horrible disease that people are going through and I want people to be cared for.

Hon. Rob Nicholson: I want the same thing, of course. It's important that we do focus on Alzheimer's. We know what the statistics are telling us. We know the international attempts to coordinate research into this particular area, and I don't want to lose that by all other good areas of research that we can and should be doing.

I have to make a comment as well about that Senate committee, and the criticism sometimes directed at our colleagues in the Senate. I don't want to digress from what we're talking about here, but they do come up with very good reports. In the different portfolios that I've had over the years, I very much have appreciated all the work that they have done. This is just another example of the kind of good work and good research that they produce.

Thank you.

The Chair: Time is up.

Mr. Robert Oliphant: Could I just close, Mr. Chair, by saying that there are many relatively new MPs on this committee, and I hope that they look at the “Rob show”, and look at ways that you can actually make a huge difference in Parliament by bringing bills together, by working across party lines. This is the way Parliament should work. It started with Mr. Nicholson inviting me, and that's the way we have to work.

If you're considering a private member's bill, and you drew too low in the lottery, as I did, find a nice person across the aisle and work on it.

This wouldn't have happened without the groundwork from Claude, our good friend. That is a model, and I encourage you to do it because it's fun, too.

• (0940)

Hon. Rob Nicholson: I obviously chose the right nice guy across the aisle as well, so it goes both ways.

Mr. Robert Oliphant: It's a bromance.

The Chair: It's great that you support each other so well.

We deal with some incredible subjects at this committee, and we hear some incredible testimony. The testimony we heard today and previously on this subject was really moving.

This committee hears things. We just wish that all Canadians could sit in on this committee sometimes, and hear about opioid addictions, pharmaceutical issues, and Alzheimer's disease issues. We'd probably have a much different approach to health issues if everybody could hear what we hear.

The first line responders, the paramedics, and the firefighters who land on the scene quite often, to hear their testimony, it's incredible.

Anyway, we thank you very much.

Actually, I just want to blow my own horn here a little bit. Years ago, and Mr. Nicholson might remember, I had a private member's bill to develop a brain tumour registry in Canada. There was no registry; there were no records. Doctors couldn't compare situations across the country. That was a private member's bill that passed, as yours hopefully will. It's quite gratifying to have that happen.

Thank you very much for your testimony.

We're going to take a break, and then we're going to do clause-by-clause study, and see if we can complete this.

Thank you.

• _____ (Pause) _____

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• (0945)

The Chair: We're reconvening.

I want to welcome our legislative clerk, Mr. Champagne, who is going to help us through this clause-by-clause process.

Mr. Carrie.

Mr. Colin Carrie (Oshawa, CPC): Mr. Chair, I was a little bit surprised and shocked about these amendments, and how much they're changing the real intent of the bill. The last one I have here, the fourth amendment, says to change it to the Dementia Act. Considering all the testimony that we've had, I would like to ask my colleague—

The Chair: Let's go through it clause by clause, and there may be some changes. I suspect there will be.

Mr. Colin Carrie: Where did these come from? Who was asking for this?

The Chair: Mr. Oliver.

Mr. John Oliver: Thank you for the question.

It was based on the first round of testimony, where we heard that we needed national strategies for dementia. There was a real weighting to dementia. We heard from the witnesses, the caregivers, and others that this was their focus. But I heard today that a big part of Mr. Nicholson's intent was to deal with Alzheimer's disease specifically, so I'm going to withdraw them. I'm not going to table them. They aren't on the table. I think we should do the clauses.

I'm torn between if every single disease advocacy group wants to have.... I mean, we can deal with every single type of cancer, every single type of diabetes, or every single type of anything, but is it a question of disease emphasis or the condition? It's like palliative care. I think we need a national strategy for palliative care, absolutely, and the causes of people being in palliation are multiple.

Likewise, we need a national strategy for dementia. The causes of dementia are multiple, but based on what I heard from Mr. Nicholson in terms of his intent, I think the need to leave in the reference to Alzheimer's is important. That's why I'm not tabling them. I'll make some changes through these to rebalance that a bit where I think it is a bit too weighted to Alzheimer's. Is that fair enough?

Thank you.

The Chair: Thanks to both of you.

We're going to move to clause-by-clause consideration.

Dr. Eyolfson.

Mr. Doug Eyolfson (Charleswood—St. James—Assiniboia—Headingley, Lib.): Before we go in camera, Mr. Chair, could I seek unanimous consent from the committee to have the Parliamentary Secretary to the Minister of Health present for the clause-by-clause discussion?

The Chair: I don't think we're going to go in camera. We don't have to go in camera for this.

Mr. Doug Eyolfson: We don't? Well then, that's withdrawn.

The Chair: It's been the practice of the committee to stay in public as much as we can, and I think we'll continue that. I'm glad to have our parliamentary secretary here.

Mr. Doug Eyolfson: Okay. My bad.

The Chair: I'm going to call each clause, starting with clause 2. If there are amendments to be made, I'll recognize the member proposing them. If there's discussion, we'll have our debate. If there's a clause that you don't agree with and you want it deleted, you vote against it. It doesn't require a motion to delete it; you just vote against the clause.

We are going to move to clause 2.

• (0950)

Mr. John Oliver: Are we touching the preamble?

The Chair: We'll leave the preamble and the name of the bill until the end.

We're going to start with clause 2.

Shall clause 2 carry?

Ms. Rachael Harder: I'm sorry, Mr. Chair, but really quickly, we're voting on a bill, so if I may, can I insist that hands are showing or not showing based on the vote, rather than it just being assumed?

The Chair: It makes my life easier, so yes, we'll ask people to vote. A show of hands, please.

(Clause 2 agreed to)

(On clause 3)

The Chair: Mr. Oliver.

Mr. John Oliver: The only change I would like to make is to paragraph 3(1)(a), as follows:

developing specific national objectives in order to improve the situations of persons suffering from dementia and decrease the burden of these diseases on Canadian society;

That's the one area where I was going to remove the Alzheimer's disease reference.

The Chair: What clause is that again?

Mr. John Oliver: It's clause 3, paragraph 3(1)(a):

developing specific national objectives in order to improve the situations of persons suffering from dementia and decrease the burden of these diseases on Canadian society;

The rest—(b), (c), (d), (e), (f), and (g)—are references to Alzheimer's. I was happy with those. It's just for that broad statement about decreasing the impact of dementia.

The Chair: All right.

Dr. Carrie.

Mr. Colin Carrie: I think we should just leave it the way it is, because it says "Alzheimer's disease and other forms of dementia". Our colleagues just finished testifying that this was designed to be a national strategy on Alzheimer's disease, so to take out Alzheimer's disease defeats the purpose. In having that word "and", I think it is very clear that there are other forms of dementia.

As it reads right now, it states:

developing specific national objectives in order to improve the situation of persons suffering from Alzheimer's disease and other forms of dementia and decrease the burden of those diseases on Canadian society;

I think it reads the way the authors intended it to, plus the way that we gave unanimous consent to. I don't see any reason for taking that out.

The Chair: Ms. Harder.

Ms. Rachael Harder: I would just ask Mr. Oliver to clarify why we would leave it in subclause 3(1), but in paragraph 3(1)(a) we would change it. I would like to understand the reason for that.

Mr. John Oliver: For me, paragraph 3(1)(a) was focused on dementia and living with dementia. I'm coming back to where I thought we should put the emphasis on dementia, which is what I believe the Senate report tried to do as well, to focus on dementia. The others, in terms of research related to Alzheimer's disease, are very different. That's why I was content with the rest of them. I just want to make sure that we are very clear that we are focusing on the consequences of dementia and how people live with them.

Ms. Rachael Harder: Okay.

Mr. Len Webber: Chair, I just want to clarify the vote we had with regard to the clause of the bill. I posed it publicly, but I assumed that we were voting on the amendments, so I retract my vote as a "no" on the clause in the bill. I support the clause in the bill, but now we're working on the amendments and I don't support this amendment or any of the amendments.

We just had testimony here from our witnesses from both parties. They referred to themselves as the "Rob show". They worked together on this bill for quite some time. They've had help from the industry, from the Alzheimer associations throughout the country, and now we're here in committee with all these amendments from the honourable member across.

I question where these amendments are coming from. Obviously, they're coming from the bureaucrats, through you to here, and I do—

Mr. John Oliver: There's one amendment on the floor. It's the only amendment changing—

• (0955)

Mr. Len Webber: I'm speaking to that one amendment, and then I won't have to reiterate for the next 25 amendments—or how many did we count here, 17 amendments that we have. To me, the work has been done. We're here now making amendments through bureaucrats; that's what my assumption is.

I think the groundwork has been done. To continue on with these 18 amendments is just ridiculous when the work has already been done and has been worked on by both the Liberals and the Conservatives here.

I just want to publicly state that I will not support this amendment or any other one.

Thank you.

The Chair: Ms. Harder.

Ms. Rachael Harder: Am I next on the list?

The Chair: You're the only one on the list.

Ms. Rachael Harder: Mr. Oliver, as just a point of clarification, this statement is with regard to national objectives. In your estimation, you were saying when it comes to setting our objectives,

it shouldn't just be focused on Alzheimer's primarily but on all forms of dementia. Am I understanding that correctly?

Mr. John Oliver: It was based on the first round of witnesses. They said they wanted a national dementia strategy. I asked specific questions about the balance between Alzheimer's and dementia, and in this case, I heard the first round of witnesses say very clearly that they were looking for a national dementia strategy, which I think that paragraph states.

Ms. Rachael Harder: Okay. I guess I'm taking you at your word, but if we put forward a national strategy with regard to all forms of dementia, from there the next part of that bill is encouraging greater investment in all areas of research related to Alzheimer's disease and other forms of dementia. Alzheimer's does take the lead in that paragraph, followed by all forms of dementia. Would your intent be to change that paragraph as well?

Mr. John Oliver: No. As I said at the beginning, it would only be clause 3. First of all, having heard this testimony, I've asked them not to table that first round of amendments because I think it was really important what we heard from the authors on the intent of the bill that they had. However, I also want to respect what we heard from the witnesses in the first round.

I was not going to make or ask for any other changes in clause 3 except for this one, which deals with a national strategy for dementia, which I thought was more consistent with what we heard from our witnesses.

Ms. Rachael Harder: Thank you.

The Chair: Dr. Carrie.

Mr. Colin Carrie: I hear my colleague, and I do recognize that the Senate did a lot of work on this. However, I thought I'd just ask the clerk, is this amendment even in order? The whole idea here is the national strategy on Alzheimer's disease. By taking that out, is it in order? May I ask the clerk that?

Mr. Olivier Champagne (Legislative Clerk):

I agree that it changes the bill significantly, but procedurally speaking, it's perfectly in order because it's within the scope of the bill.

Mr. Colin Carrie: Procedure is procedure, but intent is intent, right? This is the bill. This is the form in which it passed through the House. We had unanimous support. I'm really concerned that if we start to open this up, it will really take away from what Mr. Nicholson and Mr. Oliphant worked very hard on together. It's not a partisan issue here. We heard from the witnesses on how really enthusiastic they were to get through this entire process.

By doing this, I think my colleague, maybe inadvertently, is changing the entire purpose of what our two colleagues want to bring forward. We can talk procedure, and we can go back and forth on procedure, but when we're here in front of the committee, we should honour the intent of our colleagues who brought this forward and also honour the intent of our colleagues in the House of Commons who unanimously voted on this bill.

I really think we should pay attention to what the clerk said here, because we are masters of our own destiny. I think it would be prudent for us to respect what our colleagues said.

The Chair: Just a point, the House voted to send it to this committee to be examined and possibly amended. That's what our role is, and that's what we're here for. We're going to have the debate on this.

Mr. Oliver, you're up next.

Mr. John Oliver: I've been convinced by my colleagues and by the earlier comments, so I'll withdraw my proposed amendment, and we can move on.

The Chair: Thank you.

Mr. Kang.

Mr. Darshan Singh Kang: Mr. Chair, this is part of the democratic process. This is what we do. When the bill was unanimously supported in the House, it was the intent of the bill that was supported and not the whole bill. That is why we are going through it clause by clause.

•(1000)

The Chair: That's what we're doing. Are there any further comments on clause 3?

(Clause 3 agreed to)

The Chair: That's the national strategy clause, the one you're talking about and which you just discussed.

We'll move to clause 4.

(On clause 4)

Mr. John Oliver: Sorry, but I'm confused by the numbering here.

Under the national strategy, I guess it's still clause 3, but there's a two. Is it 3(2) then, the conference?

I was just confused by the layout of how we're doing this. I was looking at 3(1), national strategy, and then we have 3(2).

The Chair: Oh, sorry. Okay.

Mr. John Oliver: I do apologize, I didn't realize that was part of the clause that we were discussing. I apologize to Mr. Carrie. This is one I did hear from Mr. Oliphant that he thought should be changed.

It's simply how we populate the conference. It's representatives from, and the focus is on the Alzheimer Society, the advocacy groups, and it doesn't mention others.

I'd like to delete that or add the words "and other advocacy groups from other dementia".

Ms. Rachael Harder: Point of order, Mr. Chair.

We're on clause 3, correct?

The Chair: We passed clause 3.

Mr. John Oliver: We passed clause 3.

The Chair: We could go back to it, with unanimous consent, but it's—

Mr. John Oliver: Okay.

Mr. Ramez Ayoub (Thérèse-De Blainville, Lib.): On a point of order, I was under the impression also that clause 3 was 3(1), and then there's 3(2). That's the only paragraph that was a second—

The Chair: We haven't gone through (a), (b), (c), or (d).

I just asked if clause 3 carried. We had a show of hands, and it passed unanimously. We could go back and do it, if you request that.

Ms. Harder.

Ms. Rachael Harder: That's all just a point of order.

We're on clause 4 now.

The Chair: We're on clause 4.

Mr. Oliver.

Mr. John Oliver: I was going to make this change before. It's paragraph 4(4)(b), representatives. It's the creation of the advisory board, including representatives from...and it's limited to the Alzheimer Society of Canada and other Alzheimer advocacy groups.

I wanted to add "and other advocacy groups resulting in dementia" or we can just say "representatives from dementia advocacy groups".

The Chair: We're on 4(4)(b).

Ms. Rachael Harder: May I ask for a point of clarification?

So 3(1) is clause 1, 3(a) is clause 2, and 3(b) is clause 3.

Am I understanding correctly, or no?

The Chair: No, we're on clause 4, and that includes subclauses 4(1), 4(2), and 4(3), paragraphs 4(4)(a), (b), (c), and (d), and subclauses 4(5) and 4(6).

Ms. Rachael Harder: Okay, thank you.

The Chair: You're welcome.

Do you have an amendment to propose?

Mr. John Oliver: I propose that clause 4(4)(b) read, "representatives from dementia advocacy groups".

The Chair: Do you want to take out the reference to "Alzheimer Society"?

Mr. John Oliver: Yes. It would just read "representatives from dementia advocacy groups".

The Chair: Do you want to explain your amendment?

Mr. John Oliver: It's because there are so many other forms of dementia, as we heard from the first round of witnesses. There's Huntington's, Parkinson's, vascular dementia, and there's a whole list of other causes of dementia, albeit Alzheimer's is the greatest cause. There are lots of others. I think they would be quite disappointed if they were not represented and didn't have a voice on an advisory board to the minister.

The Chair: Okay.

We're just going to debate this amendment, and then we'll come to you, Ms. Blaney. I think you have an amendment.

You want to speak to this amendment.

Ms. Rachel Blaney: I appreciate the change. The important thing to remember is that the two witnesses here talked deeply about hoping to see a cure happen. If that day comes, and hopefully it will come soon, it's important to remember that other dementias need to be addressed. If we don't have space in here that refers to all forms of dementia, then happily the day will come when Alzheimer's won't be an issue, and I'm concerned that we will lose those opportunities for those other communities. So, I support that amendment.

• (1005)

The Chair: Ms. Harder.

Ms. Rachael Harder: I apologize.

Mr. Oliver, I do need you to clarify for me exactly what you're proposing to change here.

Mr. John Oliver: Shall I repeat that again, then?

Ms. Rachael Harder: Sorry. I just need you to clarify for me exactly the change that you're trying to make.

Mr. John Oliver: It's under 4(4)(b). We're dealing with the creation of an advisory board with no more than 15 members. I'm proposing that the representation on the advisory board be more inclusive than just the Alzheimer Society and Alzheimer advocacy groups.

I also heard from Mr. Oliphant that we shouldn't have in a bill the exact name of the society because names change. I was changing this to "representatives from dementia advocacy groups", so that Huntington's could be included, Parkinson's could be included, vascular dementia, and all those other forms and causes of dementia would have a say at the table. It wouldn't just be the Alzheimer groups.

Ms. Rachael Harder: Could you clarify for me if there's a specific line that you're looking to change?

Mr. John Oliver: Yes. It's 4(4)(b).

Ms. Rachael Harder: It's 4(4)(b). Okay.

You would want it to read as what?

Mr. John Oliver: "Representatives from dementia advocacy groups".

Ms. Rachael Harder: Okay. I apologize.

Thank you.

The Chair: Mr. Eyolfson, go ahead.

Mr. Doug Eyolfson: My problem with that line is not even so much the mention of Alzheimer's itself, but the fact that this may be a template for other bills dealing with specific diseases, and in it a specific organization is being named, which is unprecedented. I would not object to it if it had the word "Alzheimer's" in it to say "representatives from advocacy groups representing Alzheimer's disease and other dementias". Again, we've talked about the importance of leaving in the word "Alzheimer's". Having this specific society, this specific group named in the law, as I say, is unprecedented. They could certainly be part of this advisory group,

but to have a law that says that this particular organization has to be part of it is the problem I have with it.

I wonder if it would be agreeable to all to say, "representatives from advocacy groups for Alzheimer's and other dementias". That would keep it consistent with the rest of the bill giving this the thrust on Alzheimer's.

The Chair: Are you moving a subamendment to the amendment?

I think you are.

Mr. Doug Eyolfson: Yes.

Mr. John Oliver: I would accept that friendly amendment.

The Chair: Okay. We need you to repeat the subamendment. I think I can say that he just adds "Alzheimer's and other dementia advocacy groups".

Mr. Doug Eyolfson: Yes, representatives from advocacy groups for all—

The Chair: Without naming a society.

Mr. Doug Eyolfson: Yes, without naming a society.

The Chair: The word "Alzheimer's" is there, but the society isn't.

Mr. Doug Eyolfson: Exactly, yes.

The Chair: Perhaps we could leave that to the analysts for the final wording.

Mr. John Oliver: Doug, I heard you say, "representatives from Alzheimer advocacy groups and other dementia advocacy groups".

Mr. Doug Eyolfson: Yes.

The Chair: So it's "Alzheimer advocacy groups"—

Mr. John Oliver: —"and other dementia advocacy groups."

The Chair: Mr. Kang.

Mr. Darshan Singh Kang: Mr. Chair, I'd like to move the clock back.

With unanimous consent, we could go to clause 3, and address this in subclause 3(2). I think it would be good like that, and we could change it in clause 4 as well.

The Chair: We've passed clause 3.

Mr. Darshan Singh Kang: I was just wondering if we could, with unanimous consent, go back and change it.

The Chair: Are you seeking unanimous consent to do that?

Is there unanimous consent to go back to clause 3?

No. We don't have consent.

• (1010)

Mr. Darshan Singh Kang: Okay, thank you. I thought I'd try.

The Chair: Mr. Webber.

Mr. Len Webber: I put my hand up before the friendly amendment. I agree with you, and I'm happy with it.

The Chair: All right.

Dr. Carrie.

Mr. Colin Carrie: Yes, I was going to say that I think John and Doug came up with a good point there, so I can be supportive of that friendly amendment.

The Chair: Is there any further debate on this?

Yes, Dr. Eyolfson.

Mr. Doug Eyolfson: It just read kind of awkwardly. This says exactly the same thing. Would this say it less awkwardly? I'm not hung up on this, but it could say, "representatives of advocacy groups for Alzheimer's and other dementias". It just makes for a grammatically better sentence. I'm not hung up on it, as I say. If you prefer the original wording, I'll accept that.

The Chair: It doesn't work with the amendment if you say that.

Mr. Doug Eyolfson: Okay, then never mind. I won't gum up the works on that.

The Chair: Mr. Oliver.

Mr. John Oliver: I know we've approved clause 3, but we have the same limitations in the conference structure, where it's really just Alzheimer societies and groups that are invited to the conference, and we're excluding the other forms.

I'm wondering if I could have unanimous consent, for the amendment that was just passed, for that change in wording. Could we have unanimous consent that where it says "the Alzheimer Society of Canada and other Alzheimer advocacy groups", we have exactly the same wording inserted, that it's the Alzheimer advocacy groups and other dementia advocacy groups—whatever that wording was—just to make sure we're going to open that conference up to include those other causes of dementia?

I'm looking for unanimous consent for just that change, back in clause 3.

The Chair: We haven't passed the subamendment. We have to deal with that and then go to the amendment, and then we can go to your motion.

Mr. John Oliver: Okay.

The Chair: All in favour of the subamendment?

Mr. Colin Carrie: Could we have the final wording of the subamendment?

The Chair: Do you have the final wording?

Mr. Olivier Champagne: It was "representatives from the Alzheimer Society of Canada and other—

A voice: No, no.

The Chair: The whole point is to take out "Alzheimer Society".

Mr. Colin Carrie: It's important we get that wording if we're going to be consistent.

Mr. Olivier Champagne: Okay, so it reads, "representatives from Alzheimer advocacy groups and other dementia advocacy groups".

The Chair: All in favour of the subamendment?

(Subamendment agreed to)

The Chair: Now we're on the amendment by Mr. Oliver.

Mr. John Oliver: Again, to repeat, I'm going backwards. I need unanimous consent to go back to subclause 3(2), titled "Conference". The very last sentence describes who will be invited to the conference, and it's the same problem. We have the Alzheimer Society of Canada, the title of an agency, in there, and then it's exclusive of others.

The wording that we just passed for paragraph 4(4)(b), could we have unanimous consent to insert that into subclause 3(2)?

Mr. Len Webber: Just for clarification on that, if that's the only change, then I'm okay with it.

Mr. John Oliver: That's the only change.

The Chair: Ms. Harder.

Ms. Rachael Harder: The only difference I see is that when we go back to clause 3, it says "The Minister must, within 180 days after the day on which this act comes into force, convene a conference". It's for a one-time conference that we would insist the Alzheimer's Society of Canada be invited, whereas in clause 4, we're talking about an ongoing committee that could last up to three years.

I see the point in removing it from there because it's an ongoing committee, but in terms of inviting the Alzheimer's Society of Canada to this one-time conference that has to take place within 180 days, I actually stand behind that.

The Chair: If there was a conference on Alzheimer's, I'm quite sure the Alzheimer Society would be the number one invitee. Look, we're working really well. We're making progress. We're making the bill better. We're making it more inclusive. Therefore, I'm going to ask for unanimous consent to change clause 3, just that one, to take the society reference out. Do I have unanimous consent to do that?

Mr. Webber.

• (1015)

Mr. Len Webber: Mr. Chair, I think we need more clarification here before we vote on this, and perhaps we could ask the clerk. Is it common to put in societies in bills, specifically targeting specific societies and putting them actually into the bill, or not?

Mr. Olivier Champagne: You would have to ask a legal drafter. I don't think there's a problem with it. It's probably not very usual, but it's legally speaking.

Mr. Len Webber: This certainly has gone through all the legal route, in being drafted and such.

Mr. Olivier Champagne: Yes, it's been drafted by some legal drafters.

Mr. Len Webber: We're here today to make these changes. To me I think it's already gone through the legal draft work, and now we're changing basically perhaps even the scope of the bill. If that's the case, then I think it would be inadmissible to make these changes.

The Chair: Mr. Oliver.

Mr. John Oliver: I'm more worried about the exclusion of the other advocacy groups from the conference. I do agree with Ms. Harder's comment about the 180 days. The Alzheimer Society of Canada is not going to change its name in 180 days. It's different from the other, so I'm wondering if the friendly amendment could be to add "and representatives from other dementia advocacy groups" at the end of that. It would be "the Alzheimer Society of Canada, and other Alzheimer advocacy groups, and other forms of dementia advocacy groups".

The Chair: I think that makes it better.

Mr. Ayoub.

Mr. Ramez Ayoub: The intention that I see is only to include, not exclude. So I'm asking very humbly the members opposite on the committee.... We did work very well, and we still want to work very well to improve the bill. The intention is to improve, not to change the bill. You can see that. I think John is doing a great job just to include the parties. I don't want to get into the legal kinds of things. There are no legal things; there is only intention.

The Chair: This has nothing to do about legal. It's a matter of being inclusive.

Dr. Carrie, you're up.

Mr. Colin Carrie: I would like to have a technical question answered for me. In subclause 3(2) where it says "conference", the last sentence says "for the purpose of developing the national strategy referred to in subsection (1)." Let's go back to subsection (1). Now the short title, so clause 1, that's not subsection (1). It's going into 3(1), correct? Is that what we're referring to?

The Chair: Subsection (1), yes. He's talking about the last sentence right there, and it refers to 3(1). What's your comment?

Mr. Colin Carrie: It is 3(1) that we're referring to there, right? We're in 3(2), but the last line in 3(2), John, says, "for the purpose of developing the national strategy referred to in subsection (1)." I just wanted to clarify that is what we're referring to there, 3(1). Now that's been clarified.

Mr. Chair, would you be so kind as to give us a couple of minutes to discuss something among ourselves?

The Chair: Sure, and you make a good point because I think subclause 3(1) supports the proposed amendment.

Mr. Colin Carrie: That's what I would like to have clarified. Can you give us a break for a second?

The Chair: We'll take a short break.

• _____ (Pause) _____

•
• (1020)

The Chair: Let's continue.

Dr. Eyolfson, you're up next.

Mr. Doug Eyolfson: My point speaks to what I said before about agreeing with Alzheimer's advocacy groups.

One of the problems that might come up is, what if this society were to change its name or if it were to cease to exist? What would that do to that; whereas, if you just leave it as general "Alzheimer advocacy groups and other dementia groups", that takes care of that potential complication.

The Chair: I shouldn't be giving the argument here, but the argument is that this is a one-shot deal 180 days from now, and I think that's where the concern is lessened dramatically.

Dr. Carrie.

Mr. Colin Carrie: First of all, I want to thank the clerk for clarifying what we were talking about, and I thank my colleagues.

We don't have a problem if you want to add...if we have unanimous consent. We have to go back to clause 3, and I don't know if the NDP is okay with that, and then add "other dementia advocacy groups" there. That would be fine with us.

The Chair: Can we read out the exact amendment?

Mr. Olivier Champagne: My understanding is that, starting on line 17, it reads:

and other care providers, people suffering from dementia as well as representatives from the lay advocacy sector, the Alzheimer Society of Canada, other dementia advocacy groups, and other Alzheimer advocacy groups,

The Chair: Is there any debate?

Yes, Ms. Harder.

Ms. Rachael Harder: Can I simplify that further? It would just read simply, on line 19:

the Alzheimer Society of Canada and other dementia advocacy groups

The Chair: I think I see nods everywhere, so can we replace that?

Mr. Webber.

Mr. Len Webber: If I can change that, I would have,

the Alzheimer Society of Canada, and other Alzheimer advocacy groups, and other dementia groups, for the purpose of developing the national strategy

• (1025)

The Chair: That just puts the words in different places.

Mr. Len Webber: There is more than one advocacy group for Alzheimer's, so we need to include them as well as the dementia groups.

The Chair: All right, now we're going to go with Mr. Webber's last suggestion, and I'm going to seek unanimous consent to change

Mr. Len Webber: I'm sorry for interrupting.

One more thing is to include subclause 3(1), rather than just subsection (1) at the end that Mr. Carrie had pointed out.

The Chair: All right, just change clause 3, but put the 3 there to clarify.

I'm advised that we don't need to.

Do we have unanimous consent to change the...?

Let's have a show of hands, please.

Mr. Darshan Singh Kang: [*Inaudible—Editor*] because you have been going back and forth too many times before we pass this. We want to have the same thing inserted in there.

Mr. Len Webber: I don't know what line it starts on—15, 16, 17, 18—

the Alzheimer Society of Canada, other Alzheimer advocacy groups, and other dementia advocacy groups, for the purpose of developing the national strategy referred to in subsection (1).

Again, I question why it's not 3(1), but if that's the case, then fine.

The Chair: Representing the Alzheimer Society of Canada, other Alzheimer advocacy groups, and other dementia advocacy groups.

All in favour of that amendment. We need a show of hands as it needs to be unanimous consent.

(Amendment agreed to)

The Chair: Look at that. We have made the bill better. Congratulations.

Thank you for that, everybody. We have improved clause 3 and now we still have not passed clause 4.

Are there any more amendments to clause 4?

Ms. Blaney, yes.

Ms. Rachel Blaney: I am proposing an amendment to subclause 4 (1), on line 23. The change would be to appoint “no more than 20”, rather than 15, “members to hold office during” and continuing on.

The Chair: On line 23.

Ms. Rachel Blaney: I want to change the number from 15 to 20.

The Chair: Do you have a reason?

Ms. Rachel Blaney: The reason is we want to make sure there is enough space for diverse groups to come and participate. Narrowing it down to 15, when you look at the size of our country.... I think it's important that we make sure there's flexibility for the minister to invite people.

The Chair: Debate on the proposed amendment.

Ms. Harder.

Ms. Rachael Harder: I have one concern, and I do see your point in trying to get as many people to the table as possible, but the problem with that is that sometimes we get so many people to the

table the voices get lost. I don't know that expanding that group serves us well in the long run.

That would be my concern there.

The Chair: Are there any other comments?

Dr. Carrie.

Mr. Colin Carrie: We do have advisory groups, and I don't know how things have been set up in the last little bit, but are there any advisory groups that have more than 15 people? Would you guys know?

The Chair: I think this is the first advisory group on this concept to be proposed.

Mr. Colin Carrie: I think in the past there was a history of advisory groups, and I'm just curious, because as Rachael said, 15 is quite a lot of people as it is. I don't know.

The Chair: I would think it would add costs to bring them in.

Ms. Harder.

Ms. Rachael Harder: I wouldn't be able to comment with any sort of expertise in terms of what advisory groups have looked like in the past. I know the Prime Minister has an advisory group with youth right now. He chose 15 people, and I don't know if there's a science behind that. My background in sociology would actually tell me the max is eight in order to hear voices, but....

The Chair: All right.

Dr. Carrie.

Mr. Colin Carrie: My understanding with some of these advisory boards, too, is that there are sometimes votes, so an odd number would be better. What if we said 19? That's so we could break a vote. We don't want them to be stuck in a tie.

•(1030)

The Chair: Are you moving a subamendment?

Mr. Colin Carrie: I would say that's a friendly subamendment, if my colleague was there.

Ms. Rachel Blaney: I just want to point out, though, that it's “up to”, so we would hope it was an odd number if there was a vote. But this won't assure in any way that this will be an odd or even number.

I think the important part here is looking at the depth and breadth of the issue, what's going to happen in different parts of Canada, what's happening on different levels of dementia. It's going to have a big impact, so it's to make sure there's a big enough table to ensure that those voices are heard. I think 20 is more representative, so I'll continue to encourage us to explore having 20 at the table.

The Chair: Is there more debate?

Mr. Ayoub.

[*Translation*]

Mr. Ramez Ayoub: I will be speaking in French.

You can put on your earphones

[*English*]

maybe for the first time, I don't know.

[Translation]

We are in the process of improving a bill. I really want us to hear from experts. However, I am not too sure if we have to agree with the one with specific expertise in leading an advisory board and who tells us that such a board should have 19 or 20 members, or with the people who have been working on this bill for months.

Just now, we were at each other's throats, so to speak. We discussed odd phrases here and there and now we are discussing how many members the advisory board has. You can see how many we are; imagine what would happen with more than 15 people around a table. Surprisingly, I find myself agreeing with Ms. Harder. Things can get complicated with more than eight people.

The bill mentions 15 people. Canada is very big, but I find that is plenty enough to allow for some efficiency. We have to respect the thoughts of those who have worked on this bill for weeks and months. They certainly considered the number of members. I don't think that there is any scientific data to tell us a board should have 15 members, or 20.

I understand the intention here, and I commend it. I don't want anyone to be excluded but I do want it to work efficiently, that's all.

Thank you.

[English]

The Chair: Thank you.

Dr. Carrie.

Mr. Colin Carrie: I was just going to point out that it's not like a sword I'm going to die on or anything like that.

Around the table we have 11 members, right? I think we do a pretty good job. I don't want to be exclusive on it, but my understanding is that with some of these boards, if they can have up to 15 members, then I can almost guarantee that they will have 15 members. My idea was just to make it a little easier on them for voting. When we come to contentious issues, we don't always agree with the government, but we do understand there are a number of votes that get things passed so that the work gets done.

That's why I recommended an odd number, and I was hoping it would be accepted as a friendly amendment, because with government, if you allow them 15, they're going to have 15, and if you allow them 25, they will have 25. At the end of the day we do pretty well with 11 around the table, so 19 sounded like a good compromise to me.

The Chair: Ms. Blaney.

Ms. Rachel Blaney: I have to do my job. I just want to point out that we have...20 is more.... I think it's important, because if we look at the provinces and territories, right now with the number that we have, we're giving one per province and territory, and then a couple will have more than one. When I look at the realities of most of our provinces and territories, we usually have a very large urban centre, and then we have a more rural and remote surrounding area. Not having those voices at the table could bring significant challenges. Again, if it's 19 or 20, I think we really need to look at fair representation and make sure those voices are there and that they are heard.

The Chair: Mr. Kang.

Mr. Darshan Singh Kang: Let's not be hung up on 19 or 20. Let's make it 21 and move on.

The Chair: We have on the table a subamendment for 19; we have an amendment for 20, and then we have the bill. I want to bring it to a vote.

The subamendment is to change it from 15 to 19?

(Subamendment negatived [See *Minutes of Proceedings*])

The Chair: Now we're going to go to the amendment taking it from 15 members to 20 members.

Yes, Mr. Webber.

• (1035)

Mr. Len Webber: Can we have some discussion on that particular amendment, or do we feel we've talked enough about it?

The Chair: Have we done the amendment, or can we still have debate on it?

Okay, you're up.

Mr. Len Webber: I'll just bring back what I brought back earlier in our discussion that the two Robs, the honourable members who put this bill together, chose 15. I'm almost certain they've discussed this and chosen this particular number. I have faith in both of these individuals, and I would not support this change to 20 or whatever the number is.

The Chair: All right. The amendment is to go from 15 members to 20 members.

(Amendment negatived [See *Minutes of Proceedings*])

The Chair: You have other amendments, Ms. Blaney.

Ms. Rachel Blaney: Thank you so much. I want to come back to the "no remuneration", and I just think that should be removed. It is subclause 4(5). We had a conversation earlier about no remuneration, and I have concerns about that. I had spoken about them already, so I won't repeat them, but I would like to strike that from the bill.

The Chair: Is there any debate on that proposed amendment?

Mr. Oliver.

Mr. John Oliver: Was your concern about compensating for travel and expenses, or did you want to see remuneration?

Ms. Rachel Blaney: I want the option for remuneration to be available, if it's to bring in somebody who has multiple challenges or concerns. If you look at the testimony that we had last week, we heard very clearly about the financial hardships that some of our caregivers are experiencing across this country. I think that just blocking that completely could bring some serious concerns to people being able to attend.

Mr. John Oliver: Yes. I did hear Mr. Oliphant say he was referencing association members and people who are doing it professionally, but for caregivers I had the same worry and limitations.

The Chair: Mr. Ayoub.

Mr. Ramez Ayoub: Yes, I'm good.

The Chair: With this text?

Mr. Ramez Ayoub: No, I'm good with the microphone.

Some hon. members: Oh, oh!

The Chair: Oh, you're good. You're too fast.

Mr. Ramez Ayoub: I want to say that, again, the bill has passed like that at first reading, second reading, and third reading. It comes here, and now we are changing quite a lot. That clause is very sensitive, I think. The meaning of that clause, we had a good explanation from Rob, and it should remain as it is right now, from my perspective.

The Chair: You actually raise a good issue. I am advised that if we move this, it will make a problem for the bill at report stage, because then it involves money, possibly, and it may not go.

Now I'm looking at the clock, and we have seven minutes of regular time. If we go overboard, all this work is for nothing. We should try to finish it up, I think, in the next seven minutes.

I am going to call for a vote on the amendment to remove the "no remuneration" subclause.

Ms. Rachael Harder: Sorry, I have a point of order. You can't call the question until everyone who is on the paper to speak has spoken to the bill.

The Chair: I'm sorry.

Ms. Harder, go ahead.

Ms. Rachael Harder: I have nothing to say.

Voices: Oh, oh!

The Chair: Perfect. Thank you. The chair appreciates your comments.

I am going to call the vote on the "no remuneration" clause.

(Amendment negated [See *Minutes of Proceedings*])

The Chair: You have another one.

Ms. Rachel Blaney: Again, I just wanted to talk about clause 6, which is the meetings. Right now, they are held twice annually. I would like to see that increased. I didn't get the change in number. I would like to see it go to four meetings. The hope is that if we have a group of 15, and then we can see people coming together and hearing those different voices from across the country. That's so important.

The Chair: Is there any debate on the amendment?

(Amendment negated [See *Minutes of Proceedings*])

(Clause 4 as amended agreed to)

(Clause 5 agreed to)

The Chair: Shall the short title carry?

Some hon. members: Agreed.

The Chair: Shall the preamble carry?

Mr. Oliver, go ahead.

• (1040)

Mr. John Oliver: In the second paragraph, it's narrowed down to "Alzheimer's disease" again. I wonder if we could say, "Whereas Alzheimer's disease and other dementias erode an individual's independence and eventually cause death" and just broaden it for those other groups and other people.

The Chair: What line is it?

Mr. John Oliver: It's line 6, I think. It's the second "whereas" paragraph: "Whereas Alzheimer's disease erodes..."

The Chair: Lines 24 and 25 refer to "Alzheimer's disease or other forms of dementia", so for consistency it would be right to put "dementia" in here as well.

Mr. John Oliver: So it's "Whereas Alzheimer's disease and other forms of dementia erode an individual's independence and eventually cause death".

The Chair: Is there any debate on the proposed amendment?

(Amendment agreed to)

The Chair: Shall the preamble carry?

Some hon. members: Agreed.

The Chair: Shall the title carry?

Some hon. members: Agreed.

The Chair: Shall the bill as amended carry?

Some hon. members: Agreed.

The Chair: Shall the chair report the bill as amended to the House?

Some hon. members: Agreed.

The Chair: Shall the committee order a reprint of the bill as amended for the use of the House at report stage?

Some hon. members: Agreed.

The Chair: Done. Thanks very much.

The meeting is adjourned.

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