

## **Dementia Dialogue: Season 3, Episode 35**

Reigniting Canada's Dementia Strategy

Transcript of interview with Mary Beth Wighton and Lisa Poole

**David** - The thirty-fifth episode of Dementia Dialogue marks World Alzheimer's Day. Today we are talking with Mary Beth Wighton and Lisa Poole co-chairs of Dementia Advocacy Canada, our leading advocacy organization of people with lived experience of dementia.

The subject of our conversation is a meeting that Dementia Advocacy had with Minister Patty Hajdu, who was Minister of Health at that time. The Minister invited Mary Beth, Lisa and 11 other members to meet with her to offer their assessment of the implementation of the National Dementia Strategy. In August 2019 Canada published its first National Strategy. In June of this year, the Minister invited Mary Beth, Lisa and her colleagues to meet with her to give their opinion on how things have unfolded.

Let's listen to Mary Beth and Lisa talk about the conversation they had with Minister Hajdu.

Thanks very much, Mary Beth and Lisa for joining in our conversation today, where we're going to talk about an important meeting that you had with the Minister of Health at the time, Patty Hajdu, regarding the status of the Dementia Strategy for Canada and some of the concerns that you had as advocates and people living with dementia and lived experience as a caregiver.

So we thought it might be an opportunity for us to reflect on some of those points and talk about how we might collectively work together to strengthen the Dementia Strategy in Canada.

Mary Beth, you've joined us, this is your third time I think on Dementia Dialogue. About a year ago, you co-hosted our Town Hall on Human Rights and Dementia, and then a little while ago we had a really delightful conversation about your autobiography on dignity and dementia.

**Mary Beth** - Thanks for having me back, David.

**David** - You're welcome.

And Lisa, thanks very much for joining today, and I'm wondering if you might just share with our listeners a little bit about your role and what brings you to the dementia advocacy table?

**Lisa** - Well, thank you very much for having me here, David. This is a real pleasure. I'm a big fan of your podcasts.

I am joining you from Calgary, Alberta, and my father is living with dementia and that is how I became involved in the world of dementia and met Mary Beth and other dementia advocates across Canada.

**David** – Now, you met them at the National Conference, I think Lisa, is that correct?

**Lisa** - That is correct at the National Dementia Conference. I think it was held in 2018 or 2019... It must have been 2018. And it was people from across Canada. Different stakeholders are brought together to discuss information about dementia that would be included in the creation of the National Dementia Strategy.

**David** – Mary Beth, I'm wondering if you could tell us a little bit about Dementia Advocacy Canada and what your particular role is and Lisa maybe you could address your role in the organization as well?

**Mary Beth** - Sure. So just to jump off what Lisa said, it's a grassroots organization. We appreciate the boots on the ground, understanding what's really happening at the local level and then trying to tie that in to the provincial and federal level.

That's really kind of the focus of what we do. We have over two-hundred members all across Canada, from coast to coast to coast, and some members are more busy than other members. Some are just a receiver of information, whereas some help to develop the information and develop the meetings and participate more so in that way. And very busy at the local level using DAC's (Dementia Advocacy Canada) name.

So I'm the co-chair of DAC and I've been so since the inception of time. So I work with Lisa and a couple of other great individuals on the executive board.

**David** - And Lisa, how about you? You became involved prior to the National Conference in dementia related advocacy? I know Mary Beth was deeply involved in work in Ontario related to dementia advocacy, and it was a natural evolution to kind of the national stage. I'm wondering about your background and advocacy Lisa?

**Lisa** - Yeah, well prior to that, I guess in 2017 was when I began Dementia Connections Magazine. So I guess before I even got there, maybe for about a year prior, I'd been trying to understand how the health care system works, trying to understand the supports and services that were available for people living with dementia.

And in fact, so I met Mary Beth in 2018 in Niagara at a conference, Walk With Me conference and we connected there and that situation and the National Dementia Conference, it was really powerful to meet other people that understood what we were all trying to do. And the role of people with lived experience, whether they're family care partners or living with dementia is very different from policymakers, health care professionals and researchers. Not to say that they don't all have an important part of the puzzle, but it really was pretty powerful to meet other people who understood what I was trying to do, and I understood what they were trying to do. They can't be underestimated. That's whole positive lived experience.

**David** - So, Mary Beth, I'm wondering if you might say when the meeting occurred with the Minister and who participated in that meeting.

**Mary Beth** - So one of the things before I answer that question, one of the things is that we were very excited to have people living with dementia on the Dementia Ministerial Advisory Group. So there was myself and Jim Mann. And that was really the first of its kind. So that enabled us to have that opportunity to meet with the Minister.

And then we have a second Minister now since the release of the national plan. It was interesting because this Minister came back to me because I had asked her in a meeting, in a Zoom meeting with other Ministerial Advisory members, if she ever needed someone to talk to who has dementia, Dementia Advocacy Canada would like to help facilitate that conversation.

And lo and behold, she reached out to us and said, "I have an hour and I would love to take this opportunity to chat with you". And so that was really the inception of how we even got on to her docket. (We had) nine people living with dementia and four care partners, that was our team. And then our team took it from there. And I mean, hours and hours of work. And we tried this scenario and would run it through. And some people liked it and other people didn't. And so we would try new scenarios, et cetera.

So the crew really did take it very seriously, recognized it as an opportunity to help influence the Minister of Health. And finally we kind of landed on some of the facts that we wanted and how we wanted to present it. So it was definitely a lot of work, but we were happy with how we ended up with that framework.

**David** - Well, that's interesting. I did not know that the invitation, as it were, was initiated by the Minister. So in your presentation, you focused on two particular areas; one was around the challenges that you perceived overall in the way the strategy was unfolding and then made some recommendations in three specific areas where you thought there was a real opportunity for change and progress, I guess you could say. I'm wondering if you might highlight what some of the challenges were that you brought to the attention of the minister.

**Mary Beth** - One of the big things that we really wanted the minister to understand is that we know that there is a really good strategy plan created. It's already there. So we get a good check mark for that and we feel that the plan itself is good.

However, the implementation of that really good plan, we felt it has failed. And so using school grade levels A or D, so we gave an A to the national plan itself. And then we told the Minister that for its implementation, it would receive the D.

Those are pretty big words to have been thrown at you, if you're the Minister, I would think and she really did handle it with grace when she heard it.

And then the other thing is we felt people are not taking the responsibility necessary for the lack of quality care and social support for people impacted by dementia. So going back to yes, it's federally owned and yes, we have a provincial responsibility but at the end of the day, we can't shirk it. We can't go well, that's the federal responsibility. That's theirs. We really need to come through and say let's take responsibility of this as Canadians.

**David** - Now you mentioned in your presentation about the strategy not being referenced by the Prime Minister in his mandate letters to the various Ministers and I'm wondering if he might just elaborate on the importance of that process and if the Minister responded to that point in any way.

**Lisa** - From our understanding, if something isn't specifically mentioned in the mandate letter, then it is not going to be a priority for the Minister of that portfolio. So the fact that dementia was absent from the mandate letter of the Minister of Health and every other

Minister, really sent us a message that it's not a priority for the Prime Minister in this government.

And so we were trying to help the Minister understand the reasons why we believe that it should be a priority. And I think the minister handled it very well, as Mary Beth said, she was really gracious. She certainly at no time, no matter how critical we were, she didn't argue with us. She generally said, "Yeah, you guys are right".

Whether that's going to translate into action is another conversation.

**David** - After the challenges were referenced and brought to her attention, you then made some specific recommendations in three particular areas.

**Mary Beth** - So the first one was access to rehabilitation immediately upon diagnosis to help people retain their independence. And it's interesting that Dementia Alliance International is still pushing this rehabilitation. Yet I think unfortunately, Canadians are not embracing it and not really understanding the value that rehabilitation has for someone with dementia.

We brought it up. And you may be familiar with YouQuest, which is out of Calgary and so we gave that to the Minister as a great Canadian example of what can happen with rehabilitation and use that as a guideline.

The second thing that we asked for was creation of a clearly defined health and social support pathway from diagnosis through to end of life, and that includes dementia specific system navigators with local knowledge and the ability to make referrals. That's a big mouthful.

So we're asking for things that we have asked for since I've been diagnosed, which is nine years ago. We're asking the exact same thing which is actually kind of too bad we are asking the same thing.

System navigators as well, it's incredibly important to us, and therefore we keep trying to bring it up any chance that we can. And there's all kinds of really good examples of system navigators with other diseases. So this isn't pulling something out of the air that we think can work. It's been proven to work. And so that's another important thing. The local knowledge, I mean we know what that's like. It's piecemeal. So basically two lines, but it holds a lot of stuff.

And then the third and the final one was recognizing the needs of people impacted by dementia beyond health care. It's not just about our health, right? There's all the emotional stuff to it as well.

**David** - Yes. And the practical parts of income, income support programs, housing options for people that fall outside of the jurisdiction of one Minister and then falls through the cracks because it's not a big enough issue in a large ministry, but it is a very big issue in the experience of people that have the condition.

**Mary Beth** - And it does David, and I think Lisa is going to take it from here, but it really does cross all those Ministers, ministries and to your point, if we're not kind of duct taped all together, then it does fall through the cracks.

**David** – Lisa, one of the recommendations bolded in the document was around the formation of an all party caucus. What lay behind that recommendation of an all party caucus? What was the thinking behind that? Because it is fairly unique in some ways that that should be a recommendation about how to move forward.

**Lisa** - Well, as Mary Beth just mentioned, dementia is more than just health, and people living with dementia don't want to be defined by dementia. And so dementia is a non-partisan condition, and it requires the collaboration of all the federal ministries and all levels of government.

And when we started preparing for our meeting with the Minister, like we went through all the different departments of the different ministries, and it was actually quite fascinating. Without really digging very deeply, there's the Minister of Aboriginal Affairs, the Minister of Infrastructure and Communities, Minister of Finance, of the Employment, Workforce Development and Disability, Inclusion of Diversity and Inclusion, and Youth Ministry of Families. I mean, we can go on and on. But we need all those ministries working together around the issues that pertain to dementia. And you think then if we have that kind of cross-party and cross-ministerial collaboration, then we can probably have a better chance of implementing the National Dementia Strategy.

And as Mary Best said, it actually is an excellent strategy that Canadians should be proud of and a lot of really good work. A lot of smart people were involved in creating the strategy. And so it is deeply disappointing to think that first of all, their time and all the money invested in creating this strategy is basically wasted. But also a roadmap exists of what should and could happen to improve the lives of people living with dementia and their families. And we are very confident that if some of the well, if the entire strategy is implemented, it will actually end up saving Canadians money.

**David** - What is your sense of the interest that other parties have in this particular issue of dementia and the National Strategy?

**Lisa** – Funny you should ask because we sent all the candidates a letter or a questionnaire asking them some very specific questions about their level of interest in dementia and their knowledge of dementia. And you know, there is actually tremendous interest.

One of the things that was quite fascinating is the number of candidates that responded, saying, “You know, someone in my family is living with dementia that I understand exactly what you're talking about, and I want to see things better from a personal level as well as a government level”.

So unsurprisingly, we know that dementia is widespread and pervasive across the country. And it's not only a condition experienced by older people. Most people living with dementia in Canada are over the age of sixty-five, but there are people, as Mary Beth can attest to, who are diagnosed in their forties and younger.

**Mary Beth** - Lisa, I believe it was the Minister herself that was excited about that possibility, too, wasn't she?

**Lisa** - Absolutely. I think that she was very supportive of the idea of an all-party dementia caucus.

**Mary Beth** - I was quite pleased as being one of the focal people for the interaction and shaping up of the meeting with PHAC and the Ministers of the group. I do think they gave us a fair shake and I firmly believe they did it with grace and with really wanting us to be the best that we could be. So allowing whatever they could allow to help us do that.

It certainly seems that the group, once we finished the meeting and you hear the click that you could see the arms go, "Woo!" and it was an exciting event and you don't get too many of those of that magnitude when you have dementia or being a care partner.

**David** - But I'm wondering if you might comment on where Dementia Advocacy Canada is heading post-election.

**Lisa** - I think that we will reach out very quickly to whoever is leading the health portfolio and the portfolios of all the other ministries that we mentioned that we think intersect with dementia, just to make sure that they know we're here. We want to offer our services. We want to be a resource. We want to work with the people in decision making capacity. We want to help inform program and service development. And so that's what we will do after we know the results of the election.

**David** - How about in terms of people getting involved in some of your work?

**Lisa** - If people want to get involved, we still welcome them. We try to find what people's passion is, in what capacity, as Marybeth was mentioning earlier, some people just want information. They just want to be part of something. Other people have a real bee in their bonnet and they have something specific that they want to work towards. And so we just try to give them the tools and resources that they might need to go further with whatever idea they have or to match them with other people who share their interest.

So we try to be a flat organization. We don't want to tell people what to think or what to do. We're just trying to be a connector across the country so that if you live in the Yukon, for example, at Whitehorse, you can find other people who share some of your concerns. You can have an idea exchange; even just support one another because you understand what each other is going through.

**Mary Beth** - That internal strength really helps fight stigma. That's one of those things that you can alter the way you provide advocacy as your dementia gets worse. But it's that feeling good. It's feeling like you're contributing not just to yourself, but to people down the road. And that's powerful. When you talk about medication, advocacy is or me my number one medicine.

**Lisa** - We'd like to encourage everybody to speak up and to feel comfortable sharing their experiences and that there is no right or wrong experience and that we can all learn from one another. But if we don't speak up, then it makes it harder for things to change because we're the ones who know what it's like to be in this experience and the people who are trying to help, they, I believe, have the best of intentions and they want to help, but we need to help them understand what that means.

**Mary Beth** - That's why those thirteen people that spoke to the Minister, we'd love it to get their stories out because they're thirteen very different stories. That's what's so important. It's not a cookie cutter.

**David** - No, I know several of those people, most of those people and they have very different approaches to life and to this particular situation. But I'm always moved by the respectful listening and humor that goes on amongst people. And I think that really encourages people to become more and more open.

So, yeah, I think it's tremendous work that you're doing.

I want to thank you very much for this. It's never easy. I can minimize the amount of work or time or thought that goes into something like this. But whenever you're asked to do something like this, it does take time to prepare for the conversation. And I really appreciate the time that, first of all, that you agreed to do it. And secondly, at the time that you put into preparing for it and then our conversation today.

Her invitation to Dementia Advocacy Canada to share their thoughts, reflects well both on Minister Hajdu and on the organization.

Grassroots input like this is invaluable to both parties and they are to be thanked for the effort that went into preparing and attending the meeting.

Our show note that accompanies this episode contains links to the Strategy's documents. It also has notes that Dementia Advocacy prepared for its presentation that day. You'll want to have a look at these.

Mary Beth and Lisa invite you to become involved in the work of Dementia Advocacy Canada. You can learn more about the organization and how to get involved by going to [DementiaCanada.com](http://DementiaCanada.com)

Dementia Dialogue promotes the voice of people with lived experience to increase awareness, build understanding and enable action regarding dementia in both our personal lives and in society.

You can reach us at [dementia.dialogue@lakeheadu.ca](mailto:dementia.dialogue@lakeheadu.ca)

Thanks to the Center for Education and Research on Aging and Health at Lakehead University, our institutional sponsor and to the Public Health Agency of Canada for its financial support.

The next two episodes will see the launch of two new series. First out will be Arts and Dementia, hosted by Lisa Loiselle, who co-hosted our series on Spirituality. This will be followed by a new series on LGBTQ2S issues and dementia. It will be hosted by Arne Stinchcombe. Be sure to listen in.

My name is David Harvey.