

Dementia Dialogue; Human Rights Series, Episode 4

Human Rights and Dementia Town Hall

Transcript of Virtual Town Hall with Mary Beth Wighton and Jillian McConnell

David - Welcome to another episode of Dementia Dialogue. My name is David Harvey.

Today we are sharing some snippets from our June 29th town hall meeting on human rights and dementia. The co-hosts for our town hall were Mary Beth Wighton, who is co-chair of Dementia Advocacy Canada, a facilitator with the Behavioral Supports Lived Experience Project and a member of the Ministerial Advisory Committee on the National Dementia Strategy. Our other co-host is Jillian McConnell, who is a knowledge mobilization lead with the brainXchange. Let's listen in.

Mary Beth - Welcome to Dementia Dialogue Town Hall. Today we will be discussing human rights and dementia and the various calls to action by each of the contributors to the podcast series.

Our goal is to promote some exchange of ideas among our listeners and get your input. So we're going to do this in two parts. In part one, we will review the first four contributors, and in part two, we will finish up with the last remaining four ideas.

As we begin this discussion, it is important to realize that our Canadian National Dementia Strategy reflects a rights based approach to dementia, in fact, as it is one of the principles of the strategy. Let's acknowledge this, but also let's work to make this real.

Jillian - So the calls to action were attached to your podcast reminder, and they summarize the suggestions of each contributor about what listeners can do to promote human rights of people living with dementia. We're going to focus on one or two of the suggestions from each person for today's discussion. And while Mary Beth is reviewing the first four, I'd like you to think about which one resonates with you the most. Which ones do you feel will make the most difference?

Mary Beth - So the first one that we're going to introduce you to if you have not listened to the podcast as of yet, is Mario Gregorio. And he's a dementia activist who helped create the Canadian Charter of Rights for People with Dementia.

Mario's call was for us to get service providers to post the charter so people know their rights. The second person that was interviewed was Laura Tamblyn-Watts and what her goal is, is a suggestion is that she said ask families to speak to the media about their Covid experience and also to write to their MPs.

And along the same lines, Margaret Gillis with the International Longevity Center says we all should demand an inquiry once Covid is over.

Before we open the lines for you, Christine Telker suggested that we join organizations like Dementia Advocacy Canada.

But what I'm really seeing is getting behind everyone working together to get behind any of these ideas and move things forward that way.

Canadian Charter for Human Rights for Canadians with Dementia is absolutely imperative. And this was built on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Mario does a super job in his explanation. And I encourage you, if you haven't read or heard him speak as of yet, to hit that podcast.

Another one I like too is (well, I like them all), Laura does an excellent job about that very thing of if you don't want to join a big group or anything like that, just send an email or a letter to your MP to take that one step forward for people with dementia is a huge initiative just in itself.

Jillian - And it's interesting, Mary Beth, in terms of Laura's comments about getting involved or going to the media, writing your MP, there's various forms of media these days. Obviously, social media plays a huge role in the advocacy work that we're all doing together, you being one of the main leaders of that work. Not everybody is comfortable with going that route. So there's a number of ways in which the media can get there or you can get the message to the media, if you will. And it could be social media, but it could also be through radio, it could be through television and it could be through newspaper. And even some magazines now seem to be featuring and focusing on dementia and cognitive impairment and the rights of those that are diagnosed.

So wondering what people's thoughts are about that as well, in terms of engagement and what they might feel comfortable doing versus where they might be hesitant.

There's a couple of inquiries here. Mario's suggestion was for us to get service providers to post the charter so people actually know what their rights are. Someone has commented that Mario's suggestion of that is really important to do as early in the dementia journey as possible.

Mary Beth - Mm hmm. And I think it's not just about the education of the doctors and health care people. It's really a lot to do with helping people themselves who have dementia, understand their rights.

Kim Grier - This is Kim Grier. I'm a dementia educator and I've been in dementia care for about 30 years now. And I think one of the things that most of us who have worked in long term care and dementia care for a long time, we've all been saying, yep, needs to change, yep needs to change, yep needs to change. And very little has changed.

Even when Covid started and we were getting the horrible stories coming out of nursing homes with people dying of malnutrition and neglect and all that stuff, it's kind of like, "Well, yeah this is really bad. We better do something". And then it wasn't until the military report came out and I'm like, first of all, why did it take, even when these horror stories were coming out, for the a military report to be the one that was taken seriously? And then moving forward, given the past history of, "yes, things should change" and they haven't, this inquiry is really important because I think it needs to have teeth. It needs to have accountability. It needs to have actionable changes. It needs to be something that's in the forefront.

I mean, some of the nursing homes in Ontario, didn't they have something like 22 years to upgrade their buildings? And they still haven't done it yet. So just really interested in the is this really going to change anything? And if so, how can we all help?

Mary Beth - I think that's a really interesting comment. Is this going to actually change or is it just going to be wiped underneath the rug? This is why in particular, it is important for us to use the human rights lens, because it does have those teeth that we need.

If we can apply the Convention on the Rights of Persons with Disabilities and if we can move forward with the Convention on Ageism, then it allows Canada to be questioned and put to task basically by the World Health Organization.

When we're asking how do we do it? This is one of the methods to do this, which is putting on that international pressure on Canada to follow what they've signed up to follow, which is, again, the UNCRPD.

Jillian - So just some more comments here. Another person has mentioned about the value, the person with dementia as a human being, to encourage their voices to be heard and advocate with as well as for others. So certainly I think that that's such an important point, Mary Beth, don't you agree?

Mary Beth - I couldn't agree more. You know, I guess I'm going to sound a little bit repetitive for the next little bit but going back to human rights, we have lost, I think, some values and our own values when we are talking about and watching and listening to people living with dementia and older people, in long term care in particular.

So it is about valuing that particular person. And it doesn't matter what we have, right? Doesn't matter if we have dementia, doesn't matter if we're sick, if we're old, if we're young, if we're black, if we're white. We are people and we have to have compassion for each other and we have to have that sense of duty to fight for each other when we know that things are wrong.

As a society in Canada, we know things are wrong. So it really is very important for us to stand up as a collective to support all these individual humans for sure.

And now we're going to talk about the next four that David Harvey of Dementia Dialogue has interviewed. And so the next individual, Jane Barratt, asks that we try to speak with one voice when approaching government. So that's our first of the second half of the call to action. Deb O'Connor provided a more personal action. We really start to listen and keep listening to people with dementia. Stefanie Freil from the World Health Organization had more policy oriented advice, including creating some organizations of people with dementia. And then the final person who was interviewed was Kate Swaffer and she reiterated really the need for all of us to work together.

Jillian - Just to get us started, there was a comment provided that one participant, that's on the line with us today, that her husband is an early stage of dementia, has a long family history of Alzheimer's disease, and getting his physician to request diagnosis has been extremely challenging. They've really had to advocate diligently, just to simply get the physician's support. And I think that goes along with Deb's call to action in that starting to listen and keep listening to people with dementia. And that really needs to include our health care professionals in that equation.

Mary Beth - Yes, very much so. And I think the other thing that the challenge of finding a diagnosis is something that we talked about earlier, which is that stigma.

So if this is young onset, perhaps this person is early 50s and they don't, "Look like they have dementia", whatever that may look like. But that's that stigma. And so this can certainly throw a whole wrench into trying to get the very best care for this particular person.

Trying to attract people who have dementia, have a diagnosis, to participate in advocacy. And this is advocacy from simply writing to your MP to try and help break that stigma to very involved advocacy like at the United Nations level.

Some of the things that we've already spoke about earlier are preventers. So when someone gets that diagnosis, depending on how the doctor has introduced this diagnosis to them, either in a way that's going to inspire them to live well with dementia, *carpe diem*, grab that day in the best or has the doctor said, "You know what? Go home, get your affairs in order" and that's it.

From the very get go, I strongly believe that if a person is diagnosed in such a manner, then they're very unlikely to turn around and say, "I'm going to start to become an advocate".

One of the things that I always encourage is even if you don't join advocacy groups, be an advocate for yourself at the very minimum.

Jillian - So just jumping in, I see another comment about, or a question rather about what advocacy groups actually presently exist in Canada other than the Alzheimer Society. So, Mary Beth, I think you can speak to one specifically.

Mary Beth - Well, thank you for that introduction to Dementia Advocacy Canada. I don't know if someone can help me out and put that are being created in the chat. That would be great.

So Dementia Advocacy Canada formed recently. It's one of the newer ones. And that is about two years ago when the National Dementia Strategy Plan pulled together about two-hundred people across Canada and there was about twenty five people with dementia and care partners. We just happened to have some beer over a table, started to talk and said, "What are we doing here? Let's go. Let's make things happen".

Other groups that are also included kind of in the advocacy and self-help maybe, there's a group out of Edmonton and that's meant for young onset people. There's definitely a few, actually. Waterloo, Ontario also has one, YODA, I think?

David - Young Onset Dementia Association.

Mary Beth - I think that's it, too.

And I know our folks out in British Columbia are working extremely hard, and I believe that there's some new groups just literally starting to try and get up. And so they're reaching out to these older groups and saying, "You know, we want something a little bit more local. But how do you do this?" And that's the trick. It's about sharing resources. It's about sharing knowledge. It's about sharing leaders because we don't have a lot of leaders. So if a leader can help in some way these many groups then that's such an important thing as well.

Jillian - And I just want to mention people have been really great and throwing some other organizations into the chat pot so CanAge.ca, a new advocacy organization for senior issues.

Of course, there's Dementia Advocacy Canada, which I've posted. There's also, of course, today what we're doing, Dementia Dialogue, which is a really important resource. We can't forget about us. And the one that you were talking about with Dr. Elaine Wiersma, the Northwest Dementia Network as well.

Mary Beth - Yes, we need to work together. We absolutely need to be partners and to move the dementia pendulum along the way.

However, we both have care partners and people living with dementia, a different perspective. We have different knowledge. We have different experiences. And so this is where people living with dementia are really trying to say, "We absolutely need to represent ourselves" because the position of my care partner isn't necessarily mine. That would be theirs.

You know, when I first started doing this right back in about 2013, people living with dementia didn't even have their names used. It was the care partner's name and the person with dementia. That's what we were called. We've come a long way. We really haven't. Because now when we kind of say I want to stand up for my own rights, I can use my name. And that's when we go back to personhood, how important is that?

And the other big thing is, people when they're diagnosed may feel like, "Gee, I can't advocate because I don't have that ability anymore. I don't have that brain ability to do whatever". And this is where we really need to help people and say you have all kinds of skills. Maybe, yes, you're losing a little bit in this one area, but you have these other things and let's tap into that and let's explore them so that we can help you continue your life.

When we're talking about human rights, all of those rights are our rights. And so it comes back to, I think, a question that David said, well, how do we how do we get them? How do we move this forward?

Jillian - It's a great question and one I don't think any of us yet have the answer for. But I think the more discussions that take place like this, I think we're getting closer to the needle. I think it's getting there. And part of it in my mind is making sure that those charter rights are up front and center in every single place, every single building, every single room that you walk into so it becomes part of the culture.

Mary Beth - There you go. Culture change. Thank you.

You know, a big thank you to everyone here on the call for your participation. And we encourage you to let others know about this and other Dementia Dialogue podcasts.

And we invite you to send any suggestions for future program ideas to Dementiadialogue@lakeheadu.ca

David - I'd like to give my thanks to Mary Beth and Jillian for their leadership in today's discussion and to the meeting participants. I'd also like to remind you that there is more information on our website, Dementialogue.ca as well as links to various organizations that are providing important leadership in the area of human rights and dementia.

Our next episode in the Dementia Dialogue, we return to the mapping project and specifically the experience of people with dementia and their care partners in respect to the health care system. Our discussion will focus in particular on primary care and transitions.

Thank you very much.