

Dementia Dialogue; Human Rights Series, Episode 2

Get Real! Dementia, Gender, Age

Transcript of interview with Christine Telker, Jane Barratt and Dr. Deb O'Connor

David - You are listening to Dementia Dialogue, and my name is David Harvey.

This is the second episode in our series on human rights and dementia. In the previous episode, I forgot to mention our resource page that is on our website, DementiaDialogue.ca where you can find information about key advocacy groups and documents referred to in our program.

Today we are talking with Christine Telker, a dementia advocate and member of Dementia Alliance International.

After Christine, we will be hearing from Jane Barratt, who is secretary general of the International Federation on Aging and is a leading advocate on ageism.

Finally, our conversation will lead us to Professor Deb O'Connor from UBC, who will help us apply a human rights perspective on how we support people in long term care.

I spoke to Christine from her home in Vernon, British Columbia.

So thanks very much, Christine, for joining our conversation about human rights and dementia on Dementia Dialogue. You mentioned that you had gone to the United Nations as a representative of the Dementia Alliance International. And I'm wondering whether you might kind of give us a little bit of the background as to how you arrived at the United Nations and what was the message that you brought there?

Christine - Sure, I'd love to. Dementia Alliance International actually was, you know what I always say, a lifesaving organization for me after my diagnosis. And through working with them just by joining their support groups. And then I got actively involved in a lot of the advocating work that they do.

So Dementia Alliance International was asked to hold a side event, they call them. So we were able to present and I was chosen to go and represent them and do the speech. And it was really important that dementia finally get acknowledged and talked about. It's often an overlooked disability. So it was really important. So that's sort of how I got there.

David - OK, now, as I understand it, the dementia is covered by the United Nations Charter on the Rights of People with Disabilities. But as you said, it's been overlooked for many years. And I'm wondering if you have some insight as to why that would be the case?

Christine - I think in large part because of the stigma that surrounds dementia and the fear. So the combination of those two things, people don't want to talk about it because they're afraid of it, right?

Because the stigma around it, all most people know and hear about dementia is that end stage where you're sitting in a hallway at the end of some care home in a wheelchair, drooling, and they don't get to see the rest of the picture.

So that fear is what has created that unwillingness for people to look at it and talk about it. Women are impacted by dementia far more than men. So we have more women living with and diagnosed. And it is the fifth leading cause of death in the world. And that's listed at the World Health Organization for Women.

Why are women impacted so much more? Is it because in the last 50 years, women have taken on all these other roles that they hadn't been previously? You know, they're working full time, along with being mothers, along with being homemakers, they have these high pressure careers. And so is all of those things creating an overload of stress on women systems? Like we need to start having investigations and answering the why?

Yes, women make up about two thirds of the caregivers. So, again, there's more high stress, which may lead to more likelihood to them ending up with dementia themselves. So that's a significant number. And most of those roles being the caregiver is unpaid. All of those are pretty significant issues that need to be addressed and how to better support the women in those roles.

And as far as working in the facilities in dementia units, mostly women working in those positions, although there are more and more males starting to take on those roles and some of them do just amazing jobs. Again, those are high stress jobs, very rewarding, but very stressful. And there's lots of aspects of those jobs that are not very well addressed.

And, of course, as we have seen through this covid-19 pandemic, the whole issue surrounding the long term care and dementia care has been sort of blown wide open. And really, this is our opportunity to address all of the issues that need to be fixed and not just study it more and not just review it more. We need to actually fix it.

David - How do you think a human rights approach might contribute to that fix?

Christine - Well, there's a lot of human rights issues in long term care. And in dementia care specifically, people are on locked units, so they're segregated. Segregation was banned years ago, and yet somehow they think it's okay to segregate people with dementia. And again, that I think comes from a total lack of knowledge, education and willingness to treat people as humans should be treated. That's a big piece of it.

You can't take people and lock them away. They don't have access to fresh air and outdoors and interactions. They have very limited resources put to recreation. The rehabilitation, occupational therapies of those things just don't happen, although they say they happen, the reality is they don't happen.

I think a lot of people have to stop looking through their rose colored glasses, so to speak, and say, well, they're doing the best they can. No, actually, take your glasses off and have a really good look. You wouldn't want to live that way. So why are you accepting that it's okay for other people to be subjected to living this way?

So we really have to get real with ourselves and then we have to start demanding that our officials put the human element back into care and not make it all about dollars. And it doesn't matter whether it is a government funded facility or a private facility, they should be run on best practices for the humans they're taking charge of.

So people can start using their voices through organizations like Dementia Advocacy Canada. Start getting involved. Even if you don't have dementia yourself, chances are you know someone who does, you know someone who did. You're going to know somebody who will. One in three. So, you know, look in the mirror and look to your right and left and guess what? You might want to get involved now and make sure the changes happen.

David - Thanks very much, Christine. We are next going to be talking with Jane Barratt, who lives in Canada and can speak to how Canada compares internationally.

Jane lives in Toronto.

Jane - I'm a natural optimist but a review is only as good as the advocates behind it. So I can tell you that if there were two million people standing at Queen's Park and saying to Mr Ford that this is not right, then the world would change. And it's that kind of action that we need.

I'm hopeful and optimistic in an environment that has been a shocking uncovering of a system that has not been invested in for decades. For over 10 years now at the United Nations, there's been the open-ended working group on aging. A convention doesn't override what's going on in the country, but a convention does enable an older person and their family to actually appeal. We are hopeful coming out of these tragic, tragic series of events with the pandemic, that Canada will be a leader in the discussion and drafting of the convention, which up until now they haven't been so strong.

It does come and go, but in recent times, particularly because Canada has been so affected in terms of our older population dying, there has been greater conversations and we're hoping that it is certainly becoming one of the priorities.

There'd be nothing better than for Canada to step forward because we are known as a nation of humanity and for protecting the rights of all people. So now is the time for Canada to step forward.

And we've also got this groundswell, from our citizens, families, all the people, organizations such as those that you represent and mine. It's about what is our common agenda and the common message. So, top down/bottom up policy development is optimum.

We have a lot of work to do in Canada as it relates to long term care models. Also the care of older people, but also the health care workers. Long term care means providing services in the community all the way through to high level clinical care that some people will always need. And it's that continuum that we don't have as yet. So helping to support somebody at home is equally as important as having the high level care in a facility.

What would happen if we brought around the table ParticipAction, Rotary, Soroptimist, as well as Alzheimer's Disease association, as well as U of T (University of Toronto) and had a conversation about what's our common agenda, what can each of us bring to the table and together be a much more powerful voice when we go and talk to policymakers.

Sometimes by our very efforts to advocate, we actually split and divided in the intention. Because if you ask the question of any of those people around the table, "Who wants to be spending their last two or three years in a nursing home?", nobody would put their hand up.

Everybody has an investment. And we need to have people coming from different angles. But we need to be talking with one voice. And so we've actually got to think what is in my control, what is in my control, because there's a lot that's out of my control. So what's in it? So what can I do? I can have a strong voice. I can connect with like-minded people. And I think about family who are caring for loved ones with dementia. What is in your control? And there may be only just a small piece, the only piece maybe that you can actually go and get a cup of tea and spend 15 minutes by yourself. Well grab hold on to that, because the more you can understand what's in your control, then the better position you in to have a clear voice.

David - Thanks very much for your time and thoughts, Jane.

Finally, we are back and British Columbia and join Professor O'Connor from her home in Vancouver.

When we talk about human rights and dementia or human rights and aging, and we think of the population of people that live in long term care homes who have probably a considerable level of disability and considerable level of health needs, can you describe how you would consider social citizenship or human rights in that context?

Deb – Sure, yeah. I thought it was an interesting question, actually, because I think we think that the two are different and work in opposition. And so my first point that I thought needed to be addressed is that I don't think it's a biomedical model versus a social model. I think it's a biomedical model and a social model. And when I look at that, we need to approach long term care in a way that is integrating both. The concern is, is that right now the biomedical needs supersede the social needs and they take on a hierarchy of their own.

And so for me, what that means is recognizing that there are medical health needs for the person and refraining from attributing all behavior to those medical needs. When someone is diagnosed with dementia, it's way too common for others to just assume that the person is now vulnerable, that they're incapable and that they're in need of protection. And so we actually begin to bypass certain rights that a person has.

And so the reason for moving to a social citizenship lens, particularly to moving out of a personhood lens and into a social citizenship lens was to recognize that because somebody has a diagnosis of dementia, they don't become passive recipients of care, that dementia is not a language for saying that somebody is incapable. We interpret, society to frequently interprets it like that. And my talking to people says that that's one of the hardest things for living with dementia, is that people just automatically start to discount you.

So a social citizenship lens was to try and promote a language for thinking about people with dementia, is essentially having the same legal rights as the rest of us do. That human rights or social citizenship reinforces that. It reinforces also that people are active agents in their own life, even with things like where there might be neurodegenerative changes happening in one aspect of my brain, it doesn't mean that I can't grow in other aspects of my life, that people can continue to meaningfully participate both in their own lives and society in general. The dimension never wholly encapsulates. Nobody ever becomes the dementia. There's so many other aspects of our self identity and all of us will experience dementia in very unique and different ways and that label just doesn't capture it.

The main piece is that we look at it, that people have the right to a full life. For many people with dementia, the stigma and discrimination that they're confronted with on a daily basis often presents as one of the biggest hurdles in learning to live with dementia. So one of the first pieces for me is, is that I need to recognize that and I need to look at my role and am I playing a part in that? Then I need to begin to look at how do we counter that as a society and as individuals.

And so pieces for me, and probably this is going to be a bit repetitive, but to say we actually have to recognize that competence or capacity isn't an all or nothing concept and that people can be capable in some areas of their lives, in decision making and not in other areas. We need to assume competence in the person with dementia, irrespective of the diagnosis. And that should only change after there's clear evidence that the person is not capable rather than our typical change, which begins to treat them as incapable immediately upon hearing the diagnosis.

But more than that, also to recognize that even if there's areas where somebody may need help and may not be able to make some decisions, there will also remain areas where they are able to be making decisions in exerting control over their own lives and that we really need to be looking for those areas and making sure that we're not stepping in and taking over under the guise of taking care, when in fact we're just being being paternalistic.

So ensuring the opportunity for people to continue to contribute for as long as they're capable. And from my experience, that can go well, well into... I've worked in long term care, where people could give very clear pieces of participating in decisions about their own lives well into the disease process. And we need to be listening to those and we need to be fostering those because that's what dignified human care and rights based care is I think.

David - I'd like to thank all of our contributors today.

Remember to go to our resource page at DementiaDialogue.ca.

Our next episode will be released on June 22nd when we talk with Kate Swaffer, president of Dementia Alliance International and who is a citizen of Australia, and Stephanie Freel, a Canadian who now works with the World Health Organization in the Netherlands.

On June 26th, we will be hosting a live call-in town hall show. We hope that you can join us and you can find more information on our website. During the town hall, we will talk about the various calls to action outlined by our contributors and discuss how we might be able to advance the cause of human rights and dementia.

Thank you very much.