

## **Dementia Dialogue; Human Rights Series, Episode 1**

Absolutely Yes! Dementia and Human Rights

Transcript of interview with Mario Gregorio, Laura Tamblyn-Watts and Margaret Gillis

**David** - Welcome to Dementia Dialogue. In our next few podcasts, we will be focusing on human rights and dementia. Although people with dementia are protected by the UN Convention on the Rights of Persons with Disabilities that was adopted in 2006, it is only in the last few years that there has been a real effort to take human rights and dementia more seriously. Our focus is on Canada but we will have access to a number of world leaders who have provided guidance on this particular issue.

Much has been said about long term care during the pandemic and the gaps that have been exposed show a real difference between what we say we value and what in fact we do and actually value. As we work to change how we support people with this level of disability, Dementia Dialogue believes that a rights based perspective will help us achieve that structural change needed by providing a more solid value base.

In this first episode, we will be talking with Mario Gregorio, Laura Tamblyn-Watts and Margaret Gillis. Mario has dementia and has been a strong advocate for the human rights of people with dementia. Laura Tamblyn-Watts leads a new organization, Can Age, and has been an outspoken advocate for long term care residents, especially during this Covid 19 pandemic.

Margaret Gillis is president of the International Longevity Center in Ottawa, one of 14 centers across the world. The Longevity Center is actively lobbying the Canadian government to adopt the UN Convention on the Rights of Older Persons.

Mario, thanks very much for joining our interview on human rights and dementia and our reflection on this as part of the issues falling out of the Covid 19 pandemic. I'm wondering if you could describe how you became involved with the Alzheimer Society of Canada in the development of the Canadian Charter for Rights of Canadians with Dementia. How did your involvement come about?

**Mario** - Well, in 2015, I became a member of the Alzheimer Society, kind of the advisory group for people living with dementia. There were eight people living with dementia who evaluated the Charter of Rights from other countries like New Zealand, Australia, Ireland and the United Kingdom. We considered the ethnicity of the Canadian population. And from there, we developed a charter that is written in very plain language. It is the first ever Charter of Rights for Canadians living with dementia. It was designed to fit on one page so that medical practitioners can post it in prominent places and given to people after they're diagnosed. It was approved and released in 2018. The charters are intended for medical practitioners, but also for care providers.

**David** – Mario, what do you hope that the charter will achieve for people with dementia?

**Mario** – Thank you. This is a very good question. The stigma associated with dementia create barriers and a recent survey by the Alzheimer Society of Canada, found that almost 50 percent of Canadians do not want others to know that they have dementia. Also, about one in four Canadians said they would feel embarrassed or ashamed if they had dementia. We hope to reinforce the idea that people with dementia have the rights that are equal to any other Canadians. We also emphasized in the charter that people with dementia have the right to make decisions that are right for them.

**David** - I also wanted to ask you a little bit more about your membership on the task force on allocating resources.

**Mario** - Oh, yes, because that gave prominence on who should get the ventilator equipment. I was very disappointed to hear that people with dementia will most likely be relegated to the bottom of the list. And I want to make sure that this does not happen. We need to make sure that our voices are heard by policymakers and medical practitioners. We need to remind them of the World Health Organization and the human rights for persons with disabilities. I think we need to stand up and not allow others to treat us as second class citizens of Canada.

**David** - One of the things that I think some of our listeners will be asking themselves is what can they do to help promote the rights of people with dementia.

**Mario** - I encourage the audience who joined us today and other Canadians to get a copy of the Canadian Charter of Rights for People with Dementia, that is available at the Alzheimer Society of Canada website, and if you are a medical provider or caregiver, I hope you will post this in your facilities.

**David** – Mario's discussion of the allocation of resources is a good example of how a rights based approach can influence the outcomes for people. Mario lives in Burnaby, British Columbia, and Laura Tamblyn -Watts also joined us from British Columbia.

Thank you very much, Laura, for joining our conversation about human rights and dementia and the Covid-19, how we might be able to reconstruct this or recast this conversation in terms of people's rights. I'm wondering if you might comment on that question.

**Laura** - So my organization, CanAge, is partnered with other key stakeholders like the International Longevity Center and so on. And we work at the United Nations level on UN open ended working group that's looking to create a convention on the rights of older persons. We also work in support of the World Health Organization. And really what's important about that is that this is a rights conversation that's going on.

When it comes to those that we love, there's a significant social disconnect between, as an issue, our aging population, our aging parents and ourselves aging. And that sort of social disconnect is really interesting, intellectually and deeply problematic on a fundamental level in execution.

And so is it a human rights issue? It absolutely is a human rights issue. But there's a sort of existential piece to it, too, where we've internalized our own ageism to the point of view that we can't even understand that it's actually about us.

The World Health Organization in December, 2017 released a study that found that age is the most common form of discrimination in the world, outranking racism, outranking gender, outranking really some really robust other forms of discrimination. And so it's not like there's no other forms of racism or gender based or religious discrimination. It's rife but ageism still takes the cake in that regard.

I'm actually optimistic. I have to be. Otherwise, I don't think I could get out of bed in the morning because particularly in these terrible, terrible times where we're seeing what is an

absolutely predictable occurrence. We knew that this pandemic was going to sweep through long term care. We knew. And, at least in particular in Ontario and Quebec, we were shouting into the wind and said, you can't actually just not put personal protective equipment or testing. You can't keep the doors open in terms of staff doing two or three jobs and not understand that, particularly in accommodations which have shared rooms and shared bathing facilities, that infection control will be essentially impossible.

And yet in Ontario and Quebec, the answer publicly time and time again was that, no, it was going to go to acute care. And by saying no, it was going to go to acute care, you're saying we are not going to value the lives of older people?

Overwhelmingly in Ontario (and Quebec is a similar number), ninety percent of whom have cognitive impairment of one type (and in Ontario, it's about eighty percent have a dementia diagnosis within that. So there's a bit more) so we're saying, people who are in long term care, ninety percent of whom have cognitive impairments, are less valuable. Indeed an acceptable outcome would be that they would be struck by the pandemic and die.

And I don't know how to be more stark than that.

**David** - I'm wondering if you might answer a question that some of our listeners might have about what can they do as individuals to try and advance this situation in their community?

**Laura** - I think there's a couple of things that we can do which is unique, perhaps to the time of Covid. The first is if you can find the courage and the ability and the fit for you and your family to actually speak out to media right now. And I don't always say that, but in this particular case, we need to hear the voices of family and above all, of residents, if they're able to do that.

In this particular time, I actually do think writing your local representative and writing government actually is starting to make a difference.

The third thing I'd say is far more practical. The family councils that exist within long term care homes, if you are a family supporter and not a biological family, it's anyone who's a supporter of a resident, if you can join and be supportive of that long term care home and bring change at that space, that's really very helpful.

Another piece is when you're bringing this up, think about the change makers in your network, right? We need corporate leaders to join this conversation. We need community based organizations that don't think about older people, to change their mandate, so they think about people aging across the life course. Because so much what we have in our social service sectors is segmented by age or ability. And it's bringing that back to that human rights perspective. People are people and they're experiencing homelessness. People are people and they're experiencing hunger. People are people and they're experiencing social isolation.

So going back and looping to the other agencies or organizations you're with and ensuring that they are thinking about people aging across the life force and with different abilities. Destigmatize cognitive impairments; bring it into the other conversations of other types of either a narrative of illness or a narrative disability. We need to stop allowing people to be out of sight and out of mind and have their human rights go away with that.

**David** - Laura mentioned that CanAge, which is working with other organizations, of which one is the International Longevity Center based in Ottawa.

I first heard Margaret Gillis on CBC's power and politics. Early during the pandemic, she raised the alarm about human rights being overlooked.

So thank you very much for joining our discussion on human rights and dementia and Covid-19 that we're conducting at Dementia Dialogue.

On April the 14th, you and a number of other organizations issued a press release. And in that press release, I quote you, "There is a real and lethal impact of ageism on the fundamental human rights of older persons that have been laid bare by the pandemic".

I'm wondering if you might just elaborate on that a bit.

**Margaret** - Sure. Well, first of all, I think we need to just recognize that older people were one of the most impacted groups in the pandemic, both in Canada and around the world. And in Canada, we saw the deaths account for almost eighty percent of all the deaths in Covid-19. So it's pretty appalling. And I think we need to recognize that in the last ten weeks, we have seen nothing short than a wholesale abuse of human rights of older people in our country.

And I think we also need to recognize that this is not new, but really a continuation of some longstanding human rights issues that older people have faced in our country. So I don't think you have to look much past the news reports on long term care before the pandemic to see that there were issues faced by people in long term care. And particularly there's been a number of reports and lots of studies and nothing seems to change. So I think we've got a real issue here where we're going to have to push quite hard to make a change.

So I guess currently, in my view, there's no comprehensive international human rights convention that focuses on older persons, like there are four women or people with disabilities or children. And I think the pandemic has made the need for a convention more urgent and really more compelling.

We are of the view that the convention would provide strong protection for the rights of older people during the pandemic, both internationally and here in Canada. So if you think for a minute what we've seen during those last ten weeks, consider the people left in their beds to die without medical assistance, dealing with a horrible, violent virus that causes terrible deaths, tremendous suffering, older people dying of dehydration, dying of malnutrition or left in filthy beds. It's just incomprehensible how this could be happening in Canada, one of the richest countries in the world and one that's been acknowledged many times as being one of the best places in the world to live.

So it's been a real kind of shock, I think. You have to kind of ask yourself, how do we go from a country that had the largest per capita deaths in long term care out of fourteen developed countries, how do we go from that great country to this? And I think we also have to think about would we have ever allowed it to happen in our schools or daycares or university dorms or any other institution.

So I think now the basic point is that human rights cannot be an afterthought. It has to be up front and central. And I think really we need to establish a Covid-19 committee to inform governments and we need older people and their caregivers on those committees so that their voices were heard.

In this kind of pandemic of ageism, I'd also argue that we really need leadership to have a convention on the rights of older persons. And the reason we need that is that it would see older people as rights holders. And I don't think they've been seen as rights holders during this pandemic. It would also combat ageism. It calls ageism for what it is. It identifies it, it stops it, and it would allow the public to hold the government accountable for human rights abuses.

So, for instance, we would be able to go in front of the Human Rights Council after the pandemic and talk about what happened here and get instructions to Canada that they need to change. And I think that's really vital. We need to have that kind of a voice nowadays. So that's one of the reasons I'm quite an activist on this. And I think it also helps to promote and protect the dignity and rights of older persons. And so it's quite vital.

The other thing is we know that conventions work. We've seen it with the persons with disabilities, better access in countries all over the world, better understanding of the rights of people with disabilities. And we have certainly seen that in other areas, such as the Convention on the Rights of the Child, where child labor dropped by a third since the convention.

So it's really important. It sounds esoteric, but it's not. It's real and it has an impact.

**David** - Margaret, you've mentioned that you're encouraging people to write their members of parliament regarding the Convention on the Rights of Older Persons. I'm wondering, are there any other suggestions that you might give our listeners about how they might be able to take action related to the issues that we're talking about?

**Margaret** - I think we also need to demand, as I mentioned earlier, that there be an inquiry at the end of this, but not a long royal commission, something where they can move quickly. And so I think all of us need to also be demanding that, because what I'm really worried about, and I suspect you may be, too, is that we'll get through this crisis and everyone will forget how many older people died and that there won't be changes.

So I think it's vital to push for the human rights document, but also to make sure that there is a response by the government that's quick and fast and meaningful and has real change.

**David** - I'd like to thank you for listening to this episode. You may follow us on Facebook and on Twitter, as well as registering for Future podcast at [DementiaDialogue.ca](http://DementiaDialogue.ca)

Thank you to our partners on this series, The Center for Education and Research on Aging and Health at Lakehead University and the BrainXchange.

Our next podcast on human rights and dementia will be available on June 8<sup>th</sup>. We will discuss how this issue intersects with women's rights and also work that is going on globally at the International Federation on Aging and the World Health Organization.

Thank you.

