

## **Dementia Dialogue; Human Rights Series, Episode 3**

Include Us! A Call To Action

Transcript of interview with Stefanie Freel and Kate Swaffer

**David** - Thanks for joining Dementia Dialogue and listening to episode three of our series on human rights and dementia. My name is David Harvey.

In this episode we will look at human rights and dementia from an international viewpoint. Personally, I feel less isolated in my conviction of the legitimacy of taking a human rights based approach to dementia, when I hear that it has a basis in international law and is being advocated around the world.

To help us understand the world perspective, we are joined by Stefanie Freel, a Canadian who is a consultant with the World Health Organization, whom I spoke with at her home in the Netherlands.

Later, we will be speaking with Kate Swaffer, the president of Dementia Alliance International, who lives in Adelaide, Australia.

First, we speak with Stefanie.

**Stefanie** – Of course. Thank you very much, David. And it's a pleasure to participate in this podcast today to talk about this very important topic.

So just by means of backgrounds, you may know that in May 2017, the Global Action Plan on the Public Health Response to Dementia was adopted at the 70th World Health Assembly.

The Global Dementia Action Plan is important because it represents a commitment by member states or countries to improve the lives of people with dementia, their carers and their families, but also to create a world where people with dementia can live well, where they can receive the care and support that they need to fulfill their potential with dignity, respect, autonomy and equality.

So the Global Dementia Action Plan includes different strategic areas, seven in total, focusing on issues such as policy, dementia awareness and friendliness, risk reduction, diagnosis, treatment, care and support, support for dementia carers, information systems for dementia and dementia research and innovation.

And what's important to note also is that each of these seven strategic areas and the Global Dementia Action Plan more broadly is also grounded in various crosscutting principles. One of these crosscutting principles is focused on the human rights of people with dementia.

Another one is also focused on empowerment and engagement of people with dementia and their carers. The Global Dementia Action Plan emphasizes that policies, plans, legislation, programs and interventions developed by countries should be sensitive to the needs, expectations and human rights of people with dementia, consistent with the United Nations Convention on the Rights of Persons with Disabilities and other international and regional human rights instruments.

To provide a little bit of background, because some listeners may not be familiar with the United Nations Convention on the Rights of Persons with Disabilities (which I will refer to as the UNCRPD), this is an international human rights treaty that was adopted at the United Nations General Assembly in 2006 and that entered into force two years later in 2008. It essentially outlines an existing set of human rights that apply to all human beings, and they can be found, for example, in the International Bill of Human Rights. But it lists these together in one treaty as the impact and apply to persons with disability, including people with dementia and their caregivers.

Once diagnosed people with dementia, are often given disempowering messaging by the health and social care sectors, for example, that they should give up their jobs, education or any future plans, hopes or dreams. So for these reasons, we believe that it is of utmost importance to help improve public understanding of dementia, reduce stigma and discrimination associated with the disease, educate people about the human rights of people with dementia and the UNCRPD, and to increase public knowledge of dementia risk factors, signs and symptoms.

So in this area that we chose, working closely with civil society partners such as Alzheimer's Disease International, their national associations and governments, but also organizations led by and for people with dementia such as Dementia Alliance International, to implement dementia awareness raising programs. WHO is also working to enhance the meaningful inclusion of people with dementia in society, including their participation in activities of the wider community and to foster cultural, social and civic participation.

**David** - I wonder, Stefanie, if you might give your perspective on why the rights of people with dementia have not progressed as quickly as the rights of some other persons who are covered by the Convention on the Rights of Persons with Disabilities, which is over a decade old at this point.

**Stefanie** - I think that there are few potential reasons. The first is that I think that there is some debate within the dementia community in terms of how the term disability is defined and also its implications in terms of autonomy and dignity. So I think that that's one point.

I think that there's also another point related to the fact that the UNCRPD in many countries represents, of course, sort of an aspirational state of what is to be achieved from a mental health legislation perspective or legal provisions related to the rights of people with dementia. I think that part of that perhaps is that there is a need for closer guidance to be developed in terms of how the principles embedded with within the UNCRPD can be implemented at a national and subnational level and how they can build upon pre-existing legal mechanisms.

In my mind, those are some of the two, those are the two barriers that I would think of.

And also another initiative that is sort of related to the UNCRPD in some ways, is WHO's quality of rights initiative. And this focuses essentially on improving the quality of care and human rights in both inpatient and outpatient mental health services for people with psychosocial, intellectual and cognitive disabilities, including dementia.

The initiative seeks to create community based and recovery oriented services that respect and promote the human rights, recovery and independent living in the community, and then also empower people with mental disabilities to provide mutual support, conduct advocacy and influence policy making processes.

And so what's important is that as part of this initiative, WHO is developing a document on best practice for community based mental health services, that promotes human rights and at a second stage, this work will also specifically focus on dementia services.

**David** - Stefanie, we've been asking each of our contributors to give their ideas on what people can do to advance the cause of human rights and dementia. Do you have any thoughts on this particular question?

**Stefanie** - I think a lot of it also depends on who the eye is, right? So, for example, if the eye is someone working in government, then, of course, focusing on developing and implementing national strategies or policies that are grounded in human rights principles such as equity, dignity, inclusion, autonomy and other fundamental human rights would be very important. The inclusion of people with dementia throughout this process, as well as people with dementia as carers, would be extremely important.

Also from a government perspective, something that is very important is the implementation of mechanisms to monitor the protection of human rights, wishes and preferences of people with dementia and the implementation of legislation, as we were just discussing, in line with the objectives of the UNCRPD.

For more of a maybe civil society or community or grassroots level, advocating for the human rights of people with dementia to be an integral part of policy, services, initiatives and research, and also working on the development or implementation of awareness raising campaigns and programs that aim to reduce stigma and discrimination, as well as enhance public understanding of dementia and of the rights of those living with the disease is a sort of a clear activity that one could get involved in, either through, for example, local or subnational or national Alzheimer's associations, for example, or other organizations working in the space of dementia.

So I think from a community perspective also and drawing a little bit on what we were talking about before, thinking about how we can work towards creating more dementia inclusive societies by safeguarding the human rights of people with dementia, for example by tackling stigmatization associated with the disease, promoting greater involvement of people with dementia in society, and supporting families and carers of people with dementia is something that's very important. And in this area, we also need more organizations and initiatives that are led by and for people with dementia at national levels and to ensure that these stakeholders are really involved in all levels of decision making processes, whether it's in the policy realm, service delivery realm or research area.

**David** - My conversation with Stefanie provided some insights into how documents like the United Nations charter can be applied to government policy at the national, provincial and local level.

In turn, I spoke with Kate Swaffer, who was fully charged for our exchange at 7:00 a.m. Australia time.

Kate, I'm honored to have you join our podcast and our discussion of human rights and dementia. I know that you're a real pioneer in this field, not only in your home country of Australia, but you've risen to be a leader across the world in trying to advance the human rights of people with dementia and to make real the rights that are available to them under the Charter for the Rights of People with Disabilities. But how do you think a rights based approach will improve the lives of people with dementia?

**Kate** - Well, thanks for having me. It's great to be talking to you.

Historically, though, people with dementia have not been seen as rights bearers of the last decade. We've seen an increased focus on human rights recognition and the equal access to the UN's Convention on the Rights of Persons with Disabilities because people with dementia are people with disabilities, cognitive and other. And the CRPD requires that people with disabilities, and this has to include people with dementia, must enjoy the same rights as everyone else. And there are things like rights to autonomy and decision making, rights to live independently and there is increased pressure for these rights to be realized.

And I see many people, especially older people, the ageism that's systemic around the world, people with dementia who are over seventy-five, eighty, the other comorbidities are actually being ignored once dementia is diagnosed.

So it's a massive issue. Massive..

For women, it's more than just stigma and discrimination. If I had cancer, I know that my management and treatment would be so different. I know that my family and friends would have gathered around me to support me. But with dementia, they all walk away.

**David** – Yes. The issue of gender is also very prominent. If there were more men in long term care, there would be more action being taken, I think. There's no doubt about it.

**Kate** - I am luckily an optimist by nature, David. My name as a kid at school, a really young kid at school, was Smiley and even in the darkest places, I can usually find a reason to be joyous about life.

So I'm optimistic about life. I don't, however, think that there has been enough change for the amount of effort that people like me have put in. But sadly, even though the sector appears to be much more accepting of us, we are saying the same things, maybe differently, maybe using different language, maybe not using... the advocates in the last century weren't particularly using the language of rights and the CRPD. That's not that old, the CRPD. But we're saying the same thing they were saying, include us. I'm still, almost every week finding -not so much at the moment, only because of the Covid virus- but still having to say, "Hey, where's with the person with dementia on that program". Why is it still about us without us? So we've had advocates asking for that for twenty five years.

And still I'm asking organizations to stop having events or webinars or doing things about us, without us. We haven't had much change. The language in the media is still appalling. People have been asking not to be called sufferer's for twenty five years.

But there are things that people can do, simple things, really simple things; treat us with respect. And dementia is the only health condition I've had where there are times where I felt like a nonhuman being.

But diagnosis of dementia in the seventies was late stage. People are still thinking of it as late stage and only leading to disability and death. But people don't think about it as a disability. So we've got to move away from the pathologized or medical view of dementia and see dementia as a condition causing many acquired disabilities, not just a progressive chronic condition leading to death.

So that's what families and health care professionals need to change the way they view people with dementia. We're starting to change the attitude, but we need to change government's attitudes. We need to change advocacy organization's attitudes to support us proactively to live more positively.

And it doesn't mean we're denying that dementia is actually a terminal illness. I'm completely aware of that. And I've been told by health care professionals that I must be denying that I've got dementia and they don't understand why I'm working so hard to live positively because it's going to get me in the end. So I see every reason to keep living.

And I'm optimistic about advocacy, but I don't think there's been enough change in terms of our rights being realized. It needs to change. We all need to change and we need to work together more.

**David** - Stefanie and Kate offered some clear ideas about what we can do to advance human rights and dementia. A summary of these actions and others offered by our guests in episodes one and two are found on our resource page at [Dementiadialogue.ca](http://Dementiadialogue.ca).

On June 29<sup>th</sup> at 2:00 p.m., we are hosting a town hall to share thoughts about human rights and dementia and to review the calls to action outlined by our guests. We can also share ideas about what each of us can do and what we can do collectively through other organizations. We will be guided in our town hall by Jillian McConnell from the brainXchange and Mary Beth Wighton, a woman living with dementia and co-chair of Dementia Advocacy Canada.

You can register for the Town Hall [Dementiadialogue.ca](http://Dementiadialogue.ca)

Upcoming in July, is a multi-episode series about people's lived experience with the health care system, particularly primary care. Please join us for those episodes and we will be in touch with you to let you know when they'll be happening.

My name is David Harvey.