

Human rights for people with dementia

Kate Swaffer

MSc (Dementia Care 2014), BPsych, BA,
Grad Dip Grief Counselling , Retired Nurse
Chair, CEO, co-founder, Dementia Alliance international
PhD candidate, University of Wollongong

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Support and Advocacy: Of, by and for people with dementia

Dementia Alliance International

A global advocacy and support group, of, by and exclusively for people with dementia, advocating for the global voice and needs of people with dementia.

In collaboration with Alzheimer's Disease International, **Dementia Alliance International is the peak body for people with dementia, and the global voice of people with dementia.**



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Our Global Charter:

Living beyond dementia



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Our Vision:

A world where a person with dementia continues to be fully valued and included



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From talk to action

- I've been advocating for our human rights for many years
- Other organisations and individuals agreed with me (and then DAI), but only ever 'in principle'; no action ever followed
- Invited to speak at the WHO First Ministerial Conference on dementia, March 2015

DAI's three key demands at the WHO First Ministerial Conference in Dementia in 2015

1. We have human right to a more ethical pathway of care, including our pre and post-diagnostic care, and on pre and post vention including rehabilitation.
2. Being treated with the same human rights as everyone else, under the Disability Discrimination Acts and UN Convention on the Rights of Persons with Disabilities
3. That research does not only focus on a cure, but also on care



The need for a human rights-based approach (WHO, 2015)

“It is widely recognized that people living with dementia are frequently denied their human rights both in the community and in care homes. In many countries people living with dementia are often physically and chemically restrained, even when regulations are in place to uphold their rights. Furthermore, people living with dementia can also be victims of abuse. For example, they may be beaten for being "stubborn" or exhibiting challenging behavior. Third parties may also use a diagnosis of dementia to their own benefit, such as using deceit to acquire a person's assets.

This reflects the ethical challenges inherent in the support and protection of people living with dementia, and legislation alone will not be sufficient to ensure the protection of their rights.”



Why is the CRPD relevant to persons with dementia?

The Convention defines persons with disabilities as including *'persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.'* There can be little doubt that persons with dementia are addressed by this definition and are hence intended beneficiaries of the Convention.



In simple terms

- We are simply told to go home and die; there is nothing we can do
- We are not provided with rehabilitation or other enabling post diagnostic support
- We are not provided with the same disAbility support as every other person with a disability
- It has been, and often still is, **about us without us**

Appointing a Human Rights Advisor

- Professor Peter Mittler's academic and professional background in human rights in the disability sector, and also now a person with mild AD, has helped DAI bring this to the forefront
- Advocated that ADI and DAI prepare a paper on human rights (Neil Crowther)
- ADI Council voted this week that ADI take this further with us



It has now been agreed that ADI and DAI will work together on recommended steps internationally. At the national level you can consider using this as a tool as well... We hope that Canada will be the first country that is going to be discussed at the UN, in August 2016, and agreed to be a pilot that we can learn from.

Harnessing the United Nations Convention on the Rights of Persons with Disabilities to improve the lives of persons with dementia , Neil Crowther, 1 March 2016



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Recommendations include:

- Engaging with the United Nations Committee on the Rights of Persons with Disabilities, including through its policy making processes
- Seeking to develop productive relationships with the global network of National Human Rights Institutions
Preparing and disseminating widely a paper on the UNCRPD and the rights of persons with dementia
- Encouraging and supporting national and regional Alzheimer's organisations to participate in the examinations by the United Nations Committee on the Rights of Persons with Disabilities of their own states.

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The global voice of dementia

Thank you

www.infodai.org

@DementiaAllianc

info@infodai.org

<http://kateswaffer.com>



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