

Day 2 presentation – 8 minutes:

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Slide 1:

Distinguished guests, Ministers, ladies and gentlemen.

Thank you for the invitation to speak today; it is an honour and privilege to represent the members of Dementia Alliance International, and the global community of over 47 million people living with a diagnosis of dementia. It is important that people with dementia, in the same way as people with any other disabilities, are included as equal partners in the conversations about them. This is our basic human right.

Slide 2:

In collaboration with Alzheimer's Disease International, Dementia Alliance International has become the peak body for people with dementia globally, also working together with the Dementia Working Groups around the world. We also advocated for the World Dementia Council to invite at least one person with dementia onto the Council, and we are thrilled Hilary Doxford from the UK is a member. We welcome and appreciate this significant appointment.

I believe the People's Perspectives session yesterday in many ways set the scene for people with dementia, because our lived experience is as important as finding a cure, and although I won't share very much of my personal story, I have been a

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family carer for a number of family and friends with dementia, now deceased and am also a care recipient of services for people with dementia due to my own diagnosis. To say I have a very vested interest in dementia is perhaps an understatement!

We applaud the World Health Organisation for holding this conference, and the work of the World Dementia Council as well as ADI and everyone in attendance. Like you, we implore governments to invest more money into research, as that will save in the future, but we would hope that there is a more balanced focus in research, and not only the one after the golden egg, which is a cure. That focus excludes and denies the 47 million people currently diagnosed with dementia of better services, treatment and care.

Slide 3:

The discussions yesterday were illuminating and of great interest to people with dementia, although it was interesting to note that rehabilitation and living well with dementia were not mentioned.

ADI have a charter “I can live well with dementia’ – for this to have any traction, people with dementia believe we must all include this goal in our work.

Side 4:

As someone suggested yesterday, we all may have many issues important to bring to this meeting, but three of topics of significant importance to people with dementia are;

1. That we have human right to a more ethical pathway of care
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 on our pre and post-diagnostic care, and on pre and post vention including rehabilitation.

When I was diagnosed with dementia at the age of 49, I was told to get my end of life affairs in order, to give up work, to get acquainted with aged care, and to go home for the time I had left. I term this Prescribed Disengagement, but chose to ignore it and with support from the disability sector, engaged in authentic brain injury rehabilitation and other non-pharmacological and positive psychosocial interventions for dementia, including advocacy.

If I had been treated after a stroke, there are ethical and rehabilitative national and international guidelines; this needs to happen for dementia and thanks to ICHOM being led by Alastair Burns, this is in progress and I hope that rehabilitation

becomes part of the guidelines. It may not be a cure, but it will ensure we have a better quality of life, and I believe, research will ultimately emerge to prove it can slow the progression of dementia. If it only keeps people with dementia out of residential care for 12 months longer than we experience now, it will save governments billions of dollars. Many established mechanisms for development and assessment of clinical interventions have not been adapted to population ageing or to dementia. The time for this is now.

New, sustainable models of care that balance the role of family and government, and that overcome gender inequities, are urgently needed. Advances in information and communications technology, assistive devices, medical diagnostics, and interventions also offer much promise and it is promising that the World Dementia Council has this as part of their focus.

I have worked hard on re-empowering other people with dementia to reclaim their pre diagnosis lives, and on policy and research for dementia, on dementia friendly community initiatives in Australia, and have a particular focus on a more ethical post diagnostic pathway or model of care.

Yes I want a cure, but more importantly, I want a better quality of life for the more than 47 million people currently diagnosed with dementia, where best practice is the not norm, but still the exception. In rich western countries, this is especially unacceptable.

People with dementia also need to be at the heart of the

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conversations about them. We may not be able to march in front of our respective Parliament houses, but we are marching online in large numbers for inclusion, research, better care, and against discrimination and stigma. This is our human right.

We do not yet know whether people are living longer and healthier lives or are simply experiencing extended periods of morbidity.

Alzheimer's societies and associations around the world, and people with dementia need to use the UN Convention on the Rights of Persons with Disabilities to benefit people living with dementia. ADI in their 2012 report quite rightly highlighted this out.

It is our human right not only to person centred care, and ethical care plans, which currently we are not often offered until we need palliation – if then, in some countries - but to a system and world that stops discriminating against us. The current system of care is unpalatable and unethical, and we deserve much more.

Thank you.