

DEMENTIA WITH DIGNITY CONFERENCE

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I am grateful to Michael Woodward and his colleagues for their kind invitation to speak on the theme of dementia with dignity.

SLIDE Some of you may not know much about Alzheimer's Disease International. The vision of ADI is prevention, care and inclusion today, and cure tomorrow. We achieve that by a unique combination of global action and the local knowledge of 85 country members.

At the Global level we have had a close relationship with the World Health Organisation since the early 1980s. This resulted in an important report in 2012 Dementia: A Public Health Priority. Our dream has been to get a resolution passed by members of the World Health Assembly which will commit all stakeholders to action on dementia including by national governments, the WHO itself and civil society.

The core element of ADI is being consumer credible. Our key role is to be the vehicle through which to tell the stories of people with dementia and family carers and convey to governments the priorities of our consumer stakeholders.

It has been a long journey to get to where we are today in Australia. It was family carers who drove the dementia agenda in the 1980s and 1990s in Australia. Their focus was on improving access to services.

SLIDE And while I will be suggesting today there is much we need to do in Australia to tackle dementia, we can be proud of being the first country in the world to adopt a national policy on dementia – the Dementia Initiative in 2004. And importantly there has been bipartisan support for action on dementia most recently in the 2012 Aged Care Reforms and the additional funding for dementia research in 2013.

SLIDE It has only been since 2000 that people with dementia have been included in the life of Alzheimer's organisations and then in relatively few countries such as Scotland and Australia. Today we are just starting to understand the importance of bringing together human rights with practical action if people with dementia are to live with dignity. This can only be achieved if we are working in true partnership with people who have dementia.

There is a mass of survey information and research to suggest that the overwhelming response to dementia is negativity and fear.

The story on dementia does not start well. In Australia, as elsewhere there are strong associations with ageism and the stigma associated with dementia. As a consequence, many are subject to a 'double jeopardy'. Even as the profile of dementia rises it seems people with dementia more often than not experience discrimination and social avoidance.

The Human Rights Commission in their 2013 report *Fact or Fiction? Stereotypes of Older Australians* found that discrimination and stereotyping older Australians is fact rather than fiction with 70% of people indicating that age discrimination is common in Australia.

A Roy Morgan poll that Alzheimer's Australia commissioned this year on loneliness found that compared to the rest of the community, people with dementia are:

- more than twice as likely not see any friends
- more than three times more likely to not have a confidant
- almost three times as likely to not have a friend to call on for help

Australia is not alone. Alzheimer's Disease International (ADI) in its annual World Alzheimer Report on Stigma in September 2012 found in their survey work that about 75 percent of the participants thought that there was a stigma around people with Alzheimer's disease. In finding that stigma and social exclusion are major barriers for people with dementia and their carers the report found that worldwide:

- One quarter of people with dementia and one in ten carers admitted to hiding the diagnosis from others because of the stigma attached to the condition.
- Furthermore, 40% of people with dementia report not being included in everyday life.

SLIDE I believe the positive strategies that will make faster progress in achieving the goal of dementia with dignity are:

- Confidence in a strategic plan of action for the future - a National Strategy on Dementia. This must be appropriately funded and strategic – leading to systems level changes to the health and aged care system.
- To monitor the human rights of people with dementia within the framework of the Convention on the Rights of People with Disabilities and to implement practical action through dementia friendly communities
- To empower consumers access to new models of dementia care and better information on the quality of services and consumer experience.

National Strategy

SLIDE The dream of ADI to achieve a resolution of the World Health Assembly in May 2017 seems likely to become reality. There is a zero draft on the WHO website which has been the subject of consultation and will go to the WHO Executive in February 2017. There is a welcome focus on the human rights of people with dementia in discussion of that draft.

You can read the zero draft on the WHO website. ADI is pleased with the work done by the WHO to progress the document this far but has commented that some targets should be set higher, for example in respect of awareness and support for family carers, and for a priority to be attached to assessing the quality of dementia care. It defines seven priority areas shown on this slide and sets targets and defines action for Member States, WHO and civic society.

25 countries now have dementia plans of varying quality. So how is Australia doing in planning action for the future?

SLIDE We have a National Framework for Action on Dementia 2016 -2020 “to guide (REPEAT GUIDE) the development and implementation of actions, plans and policies to reduce the risk of dementia and improve outcomes for people with dementia and their carers.” The fact that the Framework was revised 6 years after the previous one expired says a lot about the commitment of successive governments to planning.

The framework is just that - and without action and funding it is meaningless.

Nor is there an advisory group involving the Minister and stakeholders to ensure informed action is taken for example to achieve the outcomes desired in respect of timely diagnosis or post diagnostic care. We now have annual dementia forums - but this does not adequately replace regular meetings of an advisory group providing strategic advice.

The 2012 reforms held out the hope that in respect of timely diagnosis and acute care small amounts of money would help leverage systemic change at long last. The hope has faded though there are a few green shoots for example in the work of the Australian Commission on Safety and Quality in Health Care in improving hospital care at the systems level for people with dementia.

The National Aged Care Alliance and Alzheimer’s Australia outlined the elements of a National Strategy on Dementia in the NACA 2016 Election document. It is much stronger in its vision on dementia than the Roadmap prepared by the Minister’s Aged Care Advisory Committee. NACA includes;

- Improved Community awareness
- Improved assessment and timely diagnosis
- Access to post diagnostic information and support
- Person centred care and care for those with special needs
- Improved hospital care
- An ongoing commitment to research

- The needs of special needs groups and those with mental health issues

These are elements that are included to varying degrees in the twenty-five National dementia plans around the world. But what is often lacking internationally as it is in Australia is the articulation of the rights of people with dementia and their families- including the right to appropriate health care and services.

Compare the policy commitment of the Scottish Government to timely diagnosis that has lifted diagnostic rates to about 75 per cent and their adoption of a 12 month post diagnostic guarantee to those newly diagnosed to assist in planning care and support by funding dementia coordinators.

Improving dementia care in Scottish acute hospitals has also been a key focus. At the centre of this approach is the introduction of dementia nurse consultants in 13 National Health Service boards. These nurse consultants are experts at operating at a level of strategic influence within each NHS board and have a lead role in taking forward the dementia care agenda.

SLIDE The 2016 World Alzheimer's report ***Improving healthcare for people living with dementia*** reviews research evidence on the elements of healthcare for people with dementia, and, using economic modelling, suggests how it should be improved and made more efficient.

The fact is that the majority of people with dementia have yet to receive a diagnosis, let alone treatment and care. The report recommends that ways must be found of scaling up the healthcare system while reducing the growth in costs. It suggests better balancing tasks between primary and specialist care could increase capacity and reduce costs; that evidence-based dementia care pathways should be established for dementia as they are for other chronic diseases and that the lack of research on the effectiveness of key components of dementia healthcare is striking, and should be considered an urgent priority.

Lastly, within Australia we now have a gap in government policy on dementia risk reduction. The termination of funding for Your Brain Matters was a great disappointment – such an inexpensive and positive way to promote greater awareness of the condition and possibly to reduce risk. And there has been no replacement or action to include dementia in the other preventative health messaging.

The scale of the numbers of people with dementia now and into the future demands that Australia has a National Strategy on Dementia that results in systemic and coordinated action. There will be increased expenditure on dementia in the coming decades. It is

critical to plan for it in a way that maximizes the use of the resources available to provide the best possible services to people with dementia.

Human rights

SLIDE To be inclusive of people with dementia and to respect their rights will require a change in attitudes and culture of the kind that people with disabilities and their advocates have fought for over many decades and are founded in the Convention on the Rights of Persons with Disabilities (CRPD).

Many of the concerns and frustrations that people with dementia express about the consequences of their diagnosis on their daily lives are addressed in the wide –ranging provisions of the CRPD which Australia has of course ratified. For example:

- The preamble which recognises that “disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others,”
- Article 2 on equal recognition before the law and supported decision making that respects the person’s capacity
- Article 19 on living independently and being included in the community and,
- Articles 24, 27, 28 and 30 which include comprehensive access to services including education, work, participation in recreational and sporting activities

ADI in partnership with Dementia Alliance International - an organisation of people with dementia – recently provided a briefing to the United Nations Committee on the CRPD and requested that the full resources of the UN family be used to monitor the extent to which persons living with dementia are included in the implementation of the Convention by Member States.

We received a positive hearing and there is no doubt that dementia is included within the terms of the Convention. But no country to my knowledge has monitored the rights of people with dementia in their country reporting processes under the Convention. Perhaps even more importantly- most people with dementia and their families are unaware that their rights are protected under this Convention.

There is a lack of understanding amongst service providers, health professionals and the community that dementia is a disability and how it manifests is very much dependent on the social and physical environment. Perhaps the most obvious example of this is the inappropriate use of antipsychotic medications within aged care to “control” behavioural symptoms. Often these symptoms are a result of poor environment, boredom or pain. Yet too often the first line of approach is chemical restraint through the use of medication.

It is important that Alzheimer's organisations seek partnerships with disabilities organisations in monitoring the application of the provisions of the CPRD in respect of the rights of people with dementia. In this work it will be important to look at how to give practical expression to the rights of people with dementia.

The overall principles of NDIS are in line with the CPRD developing services and supports that are consumer focused and designed to support people to achieve the goals they set for themselves. But challenges remain in implementation for example in reducing long delays in accessing NDIS for people with a progressive conditions like dementia, dealing with an onerous application process and supporting people in the early stages of dementia.

For the majority of people with dementia it seems unlikely that they will be treated with dignity and respect in their day to day lives unless our communities are more inclusive of people with dementia.

So, while it is critical we get better access to health care for people with dementia it is equally important to ensure social support and in doing so to give practical expression to human rights of people with dementia. That is why I am a strong advocate for creating dementia friendly communities.

SLIDE The concept of dementia friends and dementia friendly communities has the power to change the way we think about living with dementia. It has two different but complimentary objectives

First, to reduce stigma and promote awareness – the lived experience

Second, to empower the person with dementia to take decisions about their lives – the rights approach.

It marks a fundamental shift from a focus on meeting the physical and health needs of the person with dementia to an approach that recognises the need to support the person to achieve the best quality of life possible.

SLIDE In summary, across the world the concept of dementia friendly communities is being given practical expression in four different ways by.

1. Being **inclusive** and supporting and protecting the rights of a person with dementia.
2. Tackling **stigma** and lack of community understanding of dementia.
3. Increasing the **capability of the health and care workforce** and availability of key services.

4. Improving the **physical environment** – a topic that is central to the ageing cities movement

SLIDE The concept of dementia friendly communities and the different ways in which it has been implemented around the world is described in two Alzheimer's disease International publications on dementia friendly-communities.

Alzheimer's Australia has led a number of pilot communities and programs across the country. They have now received funding to support the development of a National Dementia Friends Program and a Dementia Friendly Communities Resource Hub.

Empowering consumers

SLIDE Over my fifteen years as CEO of Alzheimer's Australia I advocated vigorously for consumer directed care for two main reasons.

First, because I took the view that person centred care was likely to prove elusive if people with dementia and their families and carers were not equal partners with services providers in determining the services that best meet their needs.

Second, because of concerns about the lack of flexibility in services and service quality.

It is difficult to conceive of dementia with dignity if flexible services are not there when and where they are needed. And the evidence is that the aged care funding model in Australia is arguably not providing now the level of support to enable the kind of care that many people with dementia need, want and deserve.

Consumers have found that the roll-out of consumer directed care in community care has been problematic. The feedback has been that one of the results of CDC is fewer hours of care and support available in a package due to increased administrative charges.

At the same time people with dementia say they are not always being supported appropriately to be involved in decision making about their care.

We need a clearer view about the role and value of case management.

The debate about consumer directed care and empowerment is at risk of being hijacked by debate about how to achieve market based solutions.

I suggest the immediate focus of policy should be to establish a level playing field for competition between home based and residential care by delivering on the promised expansion of aged care packages and implementing a single aged care program and assessment system. This in itself is a mammoth bureaucratic task in aligning income and asset testing arrangements, ensuring a transition that protects the investments

made by the residential sector and monitoring how this approach will work within the budgetary limits set by government.

We have yet to address openly one of the unresolved dilemmas in aged care policy. If we are to really provide people with true choice between community and residential care we need more investment in home care - as when it comes to 24 hour care- institutions are cheaper. We also need not only to provide informal carers with much more support but also tackle the issue of the increasing number of people who do not have access to informal carers.

The question is do we see it as enough of a priority to spend the funds to really give people a choice between home care and institutions? For example, when people don't have an informal carer- or as care needs increase.

History suggests that as a society we are not willing to make a sufficient investment. But if that is the case can we pull the curtain aside and stop pretending that there is a real choice for most people in the later stages.

Then again- if we don't support people to be in the community regardless of level of need- are we violating Article 19 of the CPRD?

SLIDE We need a commitment from the Australian government of the kind that the Japanese have made in the reforms introduced with Long Term Care Insurance. This commitment has been to adopt models of care which embrace the principles of person centred care, flexibility in being available 24/7/365 and providing for the special needs of people with dementia where appropriate.

So there has been a big investment in community care infrastructure. Community care facilities offering 24/7/365 all-round open access, day care services, flexible 24-hour respite care, regular and on-demand health care by nurses and regular and on-demand home care by care workers. There are dementia specific day centres offer engaging activities which are person centred and attuned to individual needs and preferences.

The models are combined with intergenerational interaction that bring together LTCI funded provision with public funded facilities for the younger generation.

More recently there has been a policy emphasis in Japan on keeping older people and people with dementia healthy through new centres combining social activities (films, restaurants, games rooms) with public baths and gyms.

SLIDE Lastly it is recognized that carers and people with dementia cannot make choices without good information.

In Australia there has been a significant investment in new information gateways to capture service information but what is still lacking is transparency in the quality of care outcomes being achieved or the lived experience of older people and their families. This

is perhaps the most disappointing of all the areas of the 2012 aged care reforms, surprisingly so since a more market based approach is dependent on good information.

Australia is not alone in struggling with this issue. Worldwide there is a greater recognition that the time has come for a shift from a compliance, minimum standards approach to one that focuses on improving quality and providing information to consumers on care outcomes. Achieving this is proving hard in practice.

There are signs of change in some countries in using consumer involvement in the evaluation and accreditation of health and aged care services to both inform the process and improve consumer engagement.

For example, in England consumers work with the Care Quality Commission and are involved in accompanying inspectors on visits to services and participating in the auditing process.

Australia is now piloting three voluntary outcome indicators in residential care – namely pressure injuries, weight loss and physical restraint. Consideration is also being given to the potential of reporting to capture resident's experience and quality of life. A number of measures have been chosen and are being road-tested with providers including the ASCOT. It is questionable what level of information will be achieved in a voluntary approach which to date has had limited uptake.

But we have yet to address capturing consumer experience in using services.

Conclusion

There is a welcome and increasing focus on the human rights of people with dementia but new policies are needed to achieve dementia with dignity.

It is not enough to suggest that dementia care is a core part of mainstream aged care services. While all services should be able to respond to the needs of people with dementia the fact is that different services cater for different groups and services are needed to care for those with special dementia care needs.

New funding models needed for dementia care including respite care to better support carers and provide interest for people with dementia.

A National Strategy on Dementia needed to action change– leading to systems level changes in the health and aged care system.

Critical elements of the Strategy are monitoring the human rights of people with dementia through CRPD; dementia friendly communities; increased investment in home base care and respite and information on quality of services.

I hope to see you in Kyoto

Thank you