

DEMENTIA CARE: TURNING RHETORIC INTO REALITY

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I am grateful to CoTA for inviting me to be a keynote speaker. It is good to be here among so many old friends.

SLIDE Australia has been a leader in dementia care policy and funding. The 2004 Dementia Initiative of the Howard Government with \$320 million over 5 years, the \$270 million to tackle dementia in the 2012 aged care reforms and the most recent commitment of the Abbott Government to \$200 million for dementia research, all demonstrate the strong ongoing bipartisan commitment to addressing dementia and developing services and supports for people living with dementia.

In what I say I will suggest there have been three weaknesses in the implementation of dementia policy and services. The failure to coordinate and systemically deliver healthcare, the failure to recognise the need for flexible specialist dementia services for those with the greatest support needs and the failure to recognise the rights of people with dementia.

There is no national dementia strategy of substance to address these weaknesses. And the current and projected numbers of people with dementia warrant one. .

SLIDE The commitment to enable older people to stay at home for as long as possible is a key part of the rhetoric of aged care. Today around 70 per cent of people with dementia live in the community. Arguably many could stay longer if flexible services existed to support family carers supporting those with higher care needs through higher levels of community care packages, dementia specific respite care and other dementia services.

Choice has been the key word in the rhetoric of aged care but the meaning has shifted dramatically in recent years. Between 1986 and 2012 there was been a long and slow shift in priorities away from residential care to home based care to give the older person the choice of living at home by prioritising funding away from residential care to home based care.

The change process was given a significant boost by the promised expansion of home care packages in the 2012 aged care reforms.

The 2012 reforms changed the rhetoric around choice to empowering the consumer and to create services that are consumer driven. The idea is that consumers should be able to choose the services that best meet their needs. After 12 years of advocacy by Alzheimer's Australia and others consumer directed care has come of age on the basis of budget holding for new community packages.

The 2012 reforms re-committed to expand home care packages, greater service flexibility and a focus on quality of care outcomes.

Nearly \$270 million was committed to tackling dementia over 5 years. This included expanded Dementia Behaviour Advisory services, timely diagnosis, new dementia

supplements in community and residential care, improved acute care and support for people with younger onset dementia.

I got excited by all of this and probably got a bit ahead of myself in the expectation that the health system at last would address its responsibilities in respect of diagnosis and acute care.

There has been some progress. Dementia was made a National Health Priority Area, DBMAS services have been expanded, there has been dementia training for doctors and practice nurses, good work by the Australian Health and Safety Commission in acute care, and initial funding for younger onset dementia keyworkers.

It is not clear how much of the promised funding has been committed and the funding for Your Brian matters has been terminated.

And I cannot over-emphasise the importance of the \$200 million commitment to dementia research.

And the Turnbull Government has made a commitment to fund a \$3.9 million dementia-friendly program including a National Dementia Friends Program to promote information and understanding about dementia and a National Dementia-Friendly Community Resource Hub that will be a national clearing house of information about dementia-friendly communities and resources from around the world.

The Government has also committed to a cost-neutral approach to funding special dementia units for people with the most severe behavioural symptoms who require short-term intensive support.

SLIDE The 2016 Budget papers indicated that the Government is “committed to having an aged care system that is consumer-driven and which supports a diverse range of providers to be responsive to the care needs of older Australians.” And there is a commitment to reduce the growth in residential care funding which may impact on those with complex needs and dementia.

The short term focus is on funds following the consumer for home care packages and the integration of home care packages and home support into a single program in 2018.

To keep the hopes of aged care reform and improved dementia care services alive we need more than ever a vision that articulates for government and stakeholders the changes the reforms needed.

The 2016 Election Position Statement of the National Aged Care Alliance and the Roadmap released in March this year by the Minister’s Aged Care Advisory Committee do this although with some difference in emphasis and substance.

It seems unlikely that we will hear much from the Commonwealth Government until the Legislated Review of the 2012 reforms has taken place. It has recently been announced

that David Tune, current chair of the Aged Care Sector Committee, has been appointed to lead the review, which is due to be completed in approximately 12 months.

The vision in the Roadmap of the Governments Aged Care Sector Committee is the more radical. Their starting point is that older people and their families and carers “will have access to competent, affordable and timely care and support services through a **consumer driven, market based, sustainable aged care system.**”

The Roadmap is useful in its honesty in pointing up what would have to change if there is to be a serious intent to move to a market based and consumer driven system, even taking into account the reforms underway. And it perhaps betrays its own lack of reality in its reliance on the market in what it seeks given heavy reliance on government funding, vulnerable consumers, lack of transparency and information to support a market based approach and transition away from a highly regulated system.

The NACA position statement points in the same direction but gives greater recognition to the needs of vulnerable people, possible market failure and issues around consumer protection, safety and quality. The NACA document incorporates the work of Alzheimer’s Australia in calling for an agenda for action on dementia.

There is much to support in the vision for a single care and support system including community and residential care, consumer directed care, independent assessment and greater reliance on the market to determine the nature, location and quantity of services. This must be done carefully, however, if consumers are to be protected.

To improve the quality of dementia services within that vision requires:

- a) A National Strategy on Dementia that commits to targets, measures, timeframes and funding to action the seven priority areas in the National Dementia Framework.
- b) Monitoring the human rights of people with dementia under the Convention on the Rights of Persons with Disabilities and implementing dementia friendly communities
- c) Funding new models of care for people with dementia which respond to both the social and care needs.
- d) Publically available information for the consumer on the quality and outcomes of dementia services and the consumer experience of those services.

#### **a) National Strategy on Dementia**

SLIDE The magnitude of the impact of dementia on the healthcare system and families and carers arguably requires more than an expectation that the market will solve the problems. Market signals and knowing more about decisions consumers would make given the choice are an important as an input to policy and efficient service delivery.

But good intentions on dementia care will fail without a strategy. Alzheimer's Australia and NACA have recognised this.

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 a skeleton - 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.

Compare the policy commitment of the Scottish and UK Governments to timely diagnosis that has lifted diagnostic rates to about 75 per cent and 65 per cent respectively.

Or again the approach of the Scots in providing a 12 month post diagnostic guarantee to those newly diagnosed to assist in planning care and support.

Dementia care in Scottish acute general 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.

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.

The Australian Commission on Safety and Quality in Health Care has provided leadership and vision in improving hospital care at the systems level for people with dementia.

They have implemented the "Caring for Cognitive Impairment Campaign" which promotes awareness about the need for appropriate care and support for people with dementia in the hospital system. It provides resources which outline Actions for Health

Service Managers, Actions for Clinicians and Actions for Consumers to promote better care. More than 130 hospitals have indicated a commitment to taking action to improve care for people with dementia as part of this campaign.

The Commission has also embedded the need for better identification and care for people with cognitive impairment throughout Version 2 of the National Safety and Quality Health Service Standards.

A specific delirium clinical standard has also been developed by the Commission which identifies the key steps for preventing and providing appropriate treatment for people with dementia.

This combined approach of incorporating dementia into the standards while also providing support for increasing awareness and steps for quality improvement has the potential to transform the hospital system in terms of the care it provides for people with dementia.

I have dwelt on this example because it demonstrates a way of improving healthcare systematically at relatively low cost.

SLIDE The latest 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, we now have a gap in government policy on dementia risk reduction. And 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.

## **b) Dementia Friendly Communities and Human Rights**

The quality of life of people with dementia is unlikely to improve if the immediate consequence of a diagnosis of dementia is social avoidance and social isolation.

There needs to be an understanding that people with dementia have the right to continue to participate in community life like the rest of us, but may require some additional support to do so.

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.

SLIDE The practical outcome we are seeking 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).

Their objective is to achieve the full participation in society of people with disabilities on an equal basis with others.

Many of the concerns and frustrations that people with dementia express about their lives are addressed in the wide-ranging provisions of the CRPD. For example, in respect of decision making that respects their capacity, living in the community as independently as possible, access to health services without discrimination and opportunities for recreational and other 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.

It will be important that Alzheimer's organisations across the world including Australia seek partnerships with disabilities organisations in monitoring the application of the provisions of the CPRD in respect of the rights of people with dementia. And maybe it will be helpful in throwing a spotlight on the extent to which the National Disabilities Insurance Scheme is responding to the needs of 25000 people with younger onset 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 there are challenges in implementation. Some people have experienced long delays in accessing NDIS which is problematic for people with a progressive condition like dementia. Others have found that without support, the application process has been too onerous to overcome. Then there is also the difficulty for people who have not yet met the level of functional impairment required for eligibility.

NDIS is still in its very early days, with the Information, Linkages and Capacity (ILC) program still under development. I am pleased to hear that the NDIS has been working closely with Alzheimer's Australia to identify the teething issues in respect to supporting people with younger onset dementia.

The point is that the reform process should not be driven only by debate about market forces but by the rights of people with dementia and, for that matter, the rights of all older people, particularly those from vulnerable groups.

### **c) Dementia and the aged care reforms**

SLIDE The government position and that of the Road Map is that dementia care is integrated as core business throughout the aged care system. There is a recognition that older people with dementia have the same rights as other people but may (REPEAT MAY) require additional support to exercise choice and access services.

At one level it is a positive to have dementia recognised as core. At another the language worries me because the unkind might interpret “may require” narrowly. The battle Alzheimer’s Australia has had over time to get recognition of additional support in the form of dementia incentives in community and residential care, dementia respite and special units makes me cautious.

What does it say about future dementia care if dementia is core business now and people with dementia still struggle to get aged care services that meet their needs?

Moreover, while qualifiers are placed in the rhetoric about the market, for example the need to protect the vulnerable and for good information, I have the suspicion that there is unwarranted faith in the market to solve all problems. The invisible hand will not I fear work that well in dementia care.

Relying on a market in aged care to drive quality improvement is unrealistic for a number of reasons including:

The reality is that purchasing aged care services is fundamentally different from other consumer purchases. People are making decisions at a point of crisis and usually do not have full information to inform their decisions. Often they base their decision on location or availability rather than any information about quality. Then once they are in a facility, even if they become aware that the services are not up to par- often the trauma involved in moving services is too great. As a result people stay with a service that is less than ideal- and market forces do not work in the same way as they might for other consumer goods.

Consumer choice is a fundamental right and a critical reform but there is an important role for Government in ensuring high quality flexible services and providing consumers with the information they need to make informed decisions. So let’s talk about mixed markets.

SLIDE I look with envy at the Japanese Long Term Aged Insurance reforms implemented since 2003. They have recognised the need to focus on the needs of the person and for investment in community aged care infrastructure. For example

- Micro multi-functional community care facilities offering a care package 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.
- Dementia day centres are another endorsed LTCI community-based model. These dementia specific day centres offer engaging activities which are person centred and attuned to individual needs and preferences.
- Generic day centres (for older people) supporting 1.6 million – or 1 in 3 eligible older people.

The models are combined with intergenerational interaction that brings together LTCI funded provision with public funded facilities for the younger generation and a new policy emphasis on healthy ageing and prevention through day care centres.

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.

There is an interesting and sharp contrast between Japan which funds services through Long Term Care Insurance and Australia which increasingly will fund the consumer from the Federal Budget in the expectation that to a considerable extent, the market can be relied upon to generate services in response to demand.

It is critical in my view to seek a commitment from government to deliver much of the infrastructure needed for services which support social activities and respite services. There is also a need for dedicated additional funding to support short-term stays in special dementia units for people experiencing extreme behavioural and psychological symptoms of dementia.

#### **d) Dementia friendly information**

SLIDE 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 outcomes being achieved or the experience of older people and their families about the services they receive.

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.

Less than a third of OECD countries collect quality care indicators systematically and even fewer countries make this information available or grade the performance of service providers based on weighted quality indicators.

In Australia the focus on quality in aged care over the last few decades has been on removing the poor providers in residential care and ensuring compliance with a basic set of standards. Indeed, more than two-thirds of OECD and European countries have compulsory long term care accreditation or accreditation as a requirement for reimbursement or contracting. But it is hard to believe that a focus on compliance and basic standards will lead to the type of quality that people with dementia want and deserve.

However, there are signs of change.

Some countries are 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 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.

## **Conclusion**

My view a year or so ago was that Government needed to implement the 2012 reforms well and evaluate them properly before climbing new heights. The Legislated Review is critical to that as are the visions contained in the NACA blueprint and the Roadmap.

What actually has been the outcome of 2012 reforms in tackling dementia and how much of the funding has been committed?

We must keep a vision for aged care before the Government because we know aged care reform is never top of the political mind. And an agenda of establishing a single aged care program, independent assessment and evaluating and refining consumer directed models of care would be enough to take us well past 2020.

In respect of dementia care there is much to commend in the NACA blueprint. In my view the advocacy for improved dementia care should seek a government commitment to:

1. A National Strategy on Dementia with commitments to action on key strategic issues such as timely diagnosis enhanced acute care, specialist community and residential dementia care and dementia risk reduction overseen by a Ministerial Advisory Committee.
2. Monitor the human rights of people with dementia under the CRPD and take practical action to achieve them by implementing dementia friendly communities
3. Fund new models of care for people with dementia which respond to both their social and care needs.
4. Provide publicly available information to consumers on the quality and outcomes of dementia care services and the consumer experience of those services.

In that way we might be able to match rhetoric to reality in dementia care.

Thank you