



**Alzheimer's Disease  
International**

*The global voice on dementia*

***Dementia Care; Turning Rhetoric into Reality***

**Strengthening Dementia Services**

**Glenn Rees AM  
Chair, ADI**

# Dementia in Australia



## **A lot has happened!**

- **2004 the Dementia Initiative (\$320m over 5 years)**
- **2012 Aged Care Reforms (\$270m over 5 years)**
- **2013 Dementia Research (\$200m)**
- **A strong bipartisan approach**
- **But a failure to implement systemic health care reform, specialist dementia services and monitor the rights of people with dementia**

# The Rhetoric



- **The key word is choice**
- **To live at home for as long as possible – 70% of people with dementia live in the community.**
- **Priority away from residential to community care since 1986!**
- **Meaning of choice shifted to empowering the consumer and consumer directed community services**
- **2012 reforms promised tackling dementia in new ways special dementia care, timely diagnosis and enhanced acute care, support for younger onset dementia**
- **Some progress in hospitals and doctor training**
- **More recently limited funding for dementia friendly communities**

# Need for a Vision



**Need to have a vision if there is to be a hope of long term reform in aged care and dementia services**

- **2016 Budget commits again to an aged care system that is consumer driven and to reducing growth in residential care funding**
- **The Roadmap sets out a vision for an aged care system that is consumer driven, market based and sustainable.**
- **Can this be a reality given government funding, vulnerable groups, transition from heavy regulation**
- **The NACA 2016 Election Position Statement has a greater sense of realism about the market and a strategy for dementia.**

# Focus for National Dementia Strategy



**Much to support in a single aged care system that is consumer directed, has independent assessment and a greater reliance on the market. To improve dementia services within that framework requires**

- **A National Dementia Strategy that commits to action to systemic and coordinated change and prevention.**
- **A higher priority for dementia friendly communities and the rights of people with dementia**
- **Investment in dementia specific community and residential services**
- **Improved consumer information on service quality and outcomes**

# Focus for National Dementia Strategy



**The 2016 -2020 National Framework for Action on Dementia is no more than a GUIDE. Good intentions without strategic purpose will fail on dementia as NACA and Alzheimer's Australia have recognised**

- **We were without a plan for 6 years – 2010-2016.**
- **No Ministerial advisory group to advise and drive the action**
- **What is expected in respect of timely diagnosis acute care, prevention and respite?**
- **Compare the actions of the Scottish Govt to timely diagnosis, post diagnostic care and acute care**
- **The Australian Commission on Safety on Safety and Quality in Health Care has shown the way on the potential a systemic approach to reform**

# Why are DFCS important?



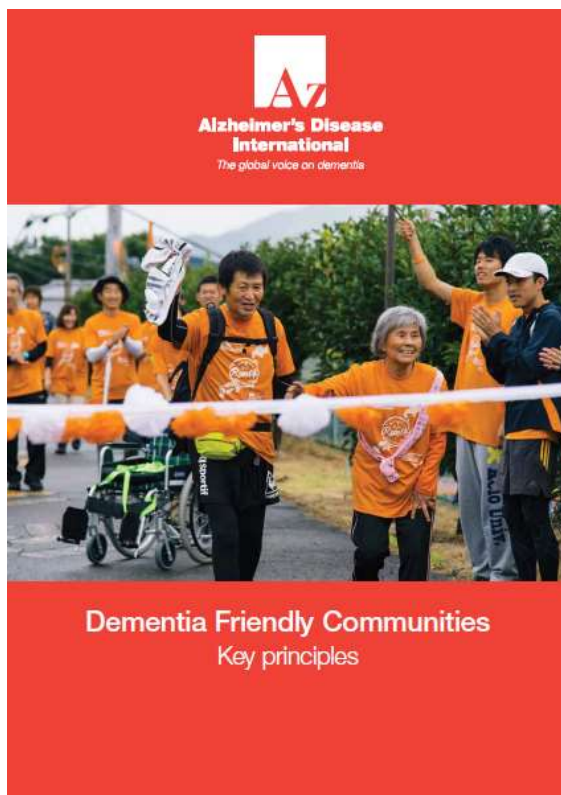
**DFCS HAVE THE POWER TO CHANGE THE WAY PEOPLE THINK ABOUT DEMENTIA**

**Two different but complementary objectives**

**1: To reduce stigma and promote awareness – the lived experience**

**2: To empower people living with dementia to take decisions about their lives – the rights approach**

# Two new Dementia Friendly Communities publications launched in 2016



[www.alz.co.uk/DFC](http://www.alz.co.uk/DFC)



# Four expressions of dementia friendliness



- **Human rights:** being inclusive and supporting and protecting the rights of a person with dementia
- **Awareness:** tackling stigma and lack of community understanding of dementia
- **Health and services:** increasing the capability of the health and care workforce
- **Improving the physical environment:** residential care, public spaces - the Ageing Cities movement

# Not just the market but rights



**People with disabilities have fought over many decades to have full participation in society on an equal basis with others.**

- **The Convention on the Rights of People with Disabilities (CRPD) includes dementia. It provides for example for:**
- **Decision making that respects their capacity**
- **Living in the community as independently as possible**
- **Access to health services without discrimination**
- **Opportunities for recreational and other activities**

**AA needs to partner with disabilities organisations to monitor CRPD including NDIS and care for people with younger onset**

# Dementia care



**Dementia specific services to enable people with dementia to stay for as long as possible in the community. Reliance on the market and the invisible hand is not enough.**

- **Doubts about the commitment in the Roadmap about the need for dementia specific services**
- **NACA recognises the need for a person centred approach and addressing the special needs of person with dementia**
- **Empower the person with dementia and their family carer to make the decisions that they need**
- **No one country has got it right but Japan is interesting**

# Japan



- **Focus on the needs of the person and priority for community care (e.g respite, transport, nursing, personal care)**
- **Funded by long term care insurance**
- **Japanese has a mix of approaches that support people with dementia**
  - Micro Multi Functional Community Care Facilities
  - 3800 Dementia day centres
  - 35,500 generic day centres – 1 in 3 eligible older people
  - Intergenerational interaction
  - New approaches to healthy ageing
- **Support and care for the person with dementia and respite for the family carer**

# Dementia friendly information



- **Information and making choices**
- **Recognition that a focus on outcomes not compliance is necessary**
- **Less than a third of OECD countries collect quality care indicators systematically**
- **Some international experience**
- **Consumer involvement in monitoring care**
- **A new focus on the experience of residents**
- **Australia developing three outcome indicators for trial in residential care and an approach to resident's experience/quality of life**

# Conclusion



**First priority to implement the 2012 reforms well and evaluate them in the Legislated Review. The NACA 2016 position statement provides a vision for improving dementia care. The priority is for:**

- **A National Strategy on Dementia including action on timely diagnosis, enhanced acute care, specialist community and residential dementia care and dementia risk reduction**
- **Priority for dementia friendly communities and action within the CRPD**
- **Investment in community infrastructure that delivers specialist dementia care services such as respite**
- **Information on the quality of dementia services**



# **Alzheimer's Disease International**

*The global voice on dementia*

 **Follow ADI on Twitter**

**@AlzDisInt @glenn\_rees**

 **Like us on Facebook**

**/alzheimersdiseaseinternational**

**Visit our website**

**[www.alz.co.uk](http://www.alz.co.uk)**

**Dementia:  
Together towards  
a new era**

Alzheimer's Disease International (ADI) and Alzheimer's Association Japan (AAJ) would like to invite you to attend the 32nd International Conference of Alzheimer's Disease International which will bring together all with an interest in dementia from around the world.



**32nd International  
Conference of  
Alzheimer's  
Disease  
International**

26 - 29 April 2017  
Kyoto, Japan  
Kyoto International  
Conference Centre



[www.adi2017.org](http://www.adi2017.org)