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GLOBAL PROGRESS, LOCAL ACTION, DEVELOPMENT OF A  
NATIONAL DEMENTIA CARE POLICY A

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My thanks to the organisers of this Conference for inviting me to speak and sincere congratulations on what I thought was an excellent day yesterday.

It is evident that at the global level there is an increasing recognition of the need for action on dementia. The idea of dementia friendly communities which is prominent on the agenda of this conference could not seriously have been contemplated at the beginning of this century.

There are seeds of hope in the fact that twenty countries now have dementia plans and ADI anticipates this will increase to twenty five by the end of this year.

Plans do not always mean action. Moreover, ADI is very conscious that many low and middle income countries have low awareness of dementia, and health and care systems that are not positioned to address the issue.

We heard in the last session yesterday two concerning perspectives.

Professor Flicker said that in his view Australia was still struggling to rebalance its aged care system away from an over investment in residential care to community based care, to achieve a system wide approach to reform and a focus on the needs of the individual.

And another from the Philippines asking the desperate question "Where can doctors refer people with dementia to for support and care?"

So despite a cautious optimism I have no reason to change my view that revolution rather than evolution is necessary to achieve the action we need to tackle dementia.

We have heard a lot about the global numbers of people with dementia at this conference and they are very concerning.

The first victory in any revolution is to persuade others to use your information and language. Alzheimer's organisations around the world have attracted the attention of governments with statistics and emotive language around epidemics.

But in the end I think it is awareness, values and philosophy rather than numbers that will be the key to achieving change and winning hearts and minds.

It is the advocacy of people with dementia and their family carers that is critical in promoting greater awareness of the lived experience of dementia in the media, in meetings with politicians and at conferences like this.

And it is the role of Alzheimer's organisations around the world to empower people with dementia and their family carers and to be the driving force of change.

We have a global group of people with dementia the Dementia Alliance International which is informing ADI and others about the experiences and views of people with dementia.

I am proud to have DAI as partners of ADI.

And I am delighted that Kate Swaffer, the chair of DAI is at this conference and taking part in the session on dementia friendly communities.

I am encouraged that there has been a change in language that embraces dementia as a public health issue, as a chronic disease, as preventable and as a social as well as a medical issue. People with dementia are not sufferers they are people who want as best they can to get on with their lives.

The point I am making, is that if we want to achieve local action and the development of a national dementia care policy, Alzheimer's organisations should start with their values, language and being inclusive of people with dementia as well as their family carers.

My starting point for talking about local action is that we all know what to do in policy terms do but are either not terribly good at doing it or lack the resources in many countries to try.

After emphasising the need for a strategic approach to tackling dementia I will focus on what I think are the four priorities at this time for local action

So what does a strategic approach look like?

Australia can be proud of being the first country in the world to acknowledge dementia as a major health issue in 2004.

Ten years on it would be true to say that tackling dementia in Australia is work in progress

In the 2004 federal budget \$320 million was committed to fund the Dementia Initiative over five years to provide training, research, Extended Aged Care at Home Dementia care packages and increased support for information and services through Alzheimer's Australia.

And there was an important commitment to tackle dementia in the 2012 aged care reforms with a further \$270 million.

There are now 20 countries with care plans in place with varying degrees of comprehensiveness and some with funding. And by the end of the year ADI is hoping there will be at least 25 plans.

These plans are the pre-condition for political awareness and future action.

In 2015 the Organisation for Economic Cooperation and Development published **Addressing Dementia** which provides an overview of policies employed by member countries to tackle dementia. The picture they draw is this. Most of the policies reported upon have their counterparts in Australia and other high income countries.

OECD concludes that ensuring that the consistent implementation of these policies remains a challenge and that there is still too much uncertainty around which policies are effective.

The ambition of ADI is that countries have a national dementia plan

ADI in the final conclusions and recommendations of the 2015 World Alzheimer Report has proposed that the elements of dementia plans necessary to support the person with dementia to stay at home for as long as possible **include:**

a) Awareness raising of dementia

b) Creation of dementia friendly communities that reduce stigma associated with the disease

c) Promotion of risk reduction measures

d) Measures to improve diagnosis and reduce the average length of diagnosis

e) Support for family carers including through information, social support, respite and counselling

f) Access to long term community and residential dementia care services and to enhanced care for people dementia in hospitals

g) A commitment to person centred care and to care that minimises the use of medical and physical restraint

h) Workforce strategies including training

i) The use of technology to assist the person with dementia in the home and to extend service reach in rural areas

j) Recognition that people with dementia deserve good quality end-of-life care with respect to their dignity and personal wishes.

This is a long list. At this time I believe there is a need to prioritise action on

- Awareness and dementia friendly societies to reduce stigma and improve the lived experience of people with dementia
- Timely diagnosis of dementia and post diagnostic support
- Support for family carers including through community care services and respite care
- Action to enhance dementia care in acute hospitals

So what can do about awareness, dementia friendly communities and organisations?

There have been exciting developments which hold promise of increasing awareness of dementia and reducing the stigma and social isolation that too often are the consequence of a diagnosis of dementia.

The dementia friends program was pioneered in Japan in 2005. It is funded and accredited by the Japanese government. There are currently 6.3 million dementia friends with a target of 8 million by 2018.

The program's aim is to transform people's perception of dementia by creating dementia friends – people drawn from all ages, cultures and lifestyles – who learn about what it is like to live with dementia, and then turn that understanding into social actions that lead to the development of dementia-friendly communities.

These social actions can take many forms, for example, by helping out in a dementia café or by raising awareness about dementia among work colleagues, family and friends. The objective is to improve the lived experience of dementia.

The program is going global. Building on Japan's lead the Alzheimer's society in the UK has been particularly active since 2013 as part of the challenge on dementia led by the Prime Minister David Cameron.

Business organisations including banks have recognised it is in their business interests to train staff and make their service more dementia friendly.

There are excellent resources to help Alzheimer's organisations develop their own approaches on the websites of the UK society and Australia. ADI will develop a set of links to this material

Logic suggests that if people do not receive a timely diagnosis and post diagnostic support their experience of dementia will be unnecessarily traumatic.

The benefits of timely diagnosis at the point when a person is concerned about their memory in terms of planning care and finances and reducing stress are well documented.

It is of great concern that as many as 35 million people living with dementia do not have a diagnosis of dementia and as a consequence are denied access to information, care and treatment.

Timely diagnosis has to be a focus for developing national dementia strategies.

Scotland has tackled this problem as a priority and has increased the rate of diagnosis to about 60 per cent. Two strategies have been employed in Scotland.

First, to set a target which can be increased over time and is monitored by the health authorities.

Second, is a post diagnostic support guarantee which gives the person with a diagnosis a guarantee of support from a named dementia link worker for 12 months?

It is this post diagnostic guarantee that is so important. Timely diagnosis needs to be supported by referral to support and care services that assist the person with dementia and the family carer.

The attraction of this guarantee from a consumer viewpoint is that it may reduce the fear of seeking a diagnosis because it gives an assurance of support.

The objective is to develop a robust personal plan that utilises all the individual's networks alongside new community support to enable each person to live well and independently with dementia for as long as possible.

This model and the Scottish approach to planning makes transparent for the consumer what they are entitled to, ensures co-ordination of services and lays the basis for relating services and support in an efficient way to the needs of the individual.

There are other important elements that contribute to supporting the person with dementia and the family carer that make the objective of staying at home for as long as possible in the community more realistic. They include training for the family carer, counselling and community based home care services and respite that are flexible and respond to the unique needs of the individual.

The most important policy foundation in aged care and dementia care policy in my view in high income countries has been in the recognition of the need for flexibility in home care and respite services.

Without flexibility, it is not possible to provide person centred services that respond to the unique needs of the person with dementia and their families. And by flexibility I mean the type of service, location, the

provider and timing of the service. There are a variety of strategies to achieve flexibility in packaging services for the individual – for example the use of care coordinators, models of consumer directed care, multi-disciplinary and coordinated services and providing cash to the consumer to buy the services they need.

Respite care is often the most demanded service by family carers of people with dementia and well-designed respite can socially engage the person with dementia.

In the design of care packages and respite family carers are looking for year round open access, day care services, regular visits by nurses and care workers.

In this way older people are able to remain in the community and avoid more expensive residential care.

Dementia care models are needed which are community-based, open throughout the year and available to people at all stages of the disease process. Some models may work on cognitive therapy and restoring capacity by offering activities which are person centred and attuned to individual needs and preferences.

Such models as are found in Japan and other high income countries. They may be combined with approaches that promote intergenerational interaction that brings together aged care and dementia services with publicly funded facilities for the younger generation including schools and child day care centres.

An important issue is dementia care in acute care

Across the world acute care systems are struggling to care for people with dementia. For example, already a quarter of hospital beds in the UK are occupied by people with dementia and many of these people are not receiving care that meets their needs.

International studies have shown that people with dementia stay in hospital almost twice as long as those without dementia and invariably have worse clinical outcomes. For example, they are twice as likely to experience falls, pressure ulcers, fractures and delirium.

Better care, communication and design, outcomes for people with dementia could be significantly improved in hospitals. The UK has prioritised improving dementia care in hospitals, including developing and improving alternatives to hospital admission.

Dementia care in Scottish acute general hospitals has been a key focus in both the first and second national dementia strategies in Scotland. The approach is comprehensive including initially a focus on a leadership structure within National Health Service boards to drive and monitor improvements, to upskill the workforce, to work as equal partners with families and minimising and to respond appropriately to stress and distress.

At the centre of this approach is the introduction of dementia nurse consultants in 13 National Health Service boards alongside 4 allied health professional consultants. 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 nurse consultants are joined by over 500 acute care dementia champions who are the operational change agents. Most of the dementia champions are nurses and allied health workers.

## Conclusions

The time is right at the local level to promote policy discussion on the social and economic impact of ageing and dementia and to formulate an agenda for action.

The OECD and ADI have set out a policy agenda that provides a starting point for national action. Countries are at different stages and the importance of planning local action is to make a start on those issues that would make the greatest difference.

I suggest that issues around awareness and dementia friendly communities, flexible home care and respite services, timely diagnosis and post diagnostic support are core priorities for planning.

At later stages there will be a need to prioritise other key issues such as end of life and palliative care and the quality of residential care.

ADI looks forward to working with the Alzheimer's Association of the Philippines and the Philippine Neurological Association to improve the quality of life of people with dementia.