

# **ALZHEIMERS ORGANISATIONS AS AGENTS OF CHANGE**

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## **I AM GRATEFUL TO ALZHEIMER'S DISEASE INTERNATIONAL (ADI) FOR THIS OPPORTUNITY TO TALK ABOUT THE DRAMATIC CHANGES NECESSARY IN ALZHEIMER'S ORGANISATIONS IF WE ARE TO BE AGENTS OF CHANGE.**

While my views are coloured by Australian experience I am reasonably confident that what I have to say has broader relevance I take the view that the role played by Alzheimer's organisations has changed dramatically over the last 10 years. The challenges we face over the coming 10 years represent an opportunity for revolution rather than evolution in the role of Alzheimer's organisations as agents of change.

The change process has started in earnest in the last decade at the national and international levels.

National organisations are documenting the extent and nature of the dementia epidemic and articulating concerns about the quality of dementia care. ADI through the publication of the World Alzheimer's Reports and more recently on early diagnosis has started to provide an essential social and economic dimension to understanding the worldwide dementia epidemic. Less developed countries continue to be constrained by their resources but in the Asia Pacific every year sees advances.

The metamorphosis of Alzheimer's Australia has involved change from a carer organisation to one of inclusive of people with dementia; an organisation focussed on its own services to one giving a higher priority to advocacy; and from a conservative organisation shy of the media, to active use of modern social media. I see similar changes in the evolution of Alzheimer's organisations elsewhere.

I have come to the view that there is a need for a revolution in the way that we think about dementia and advocate for action for two main reasons.

First, because pervasive negative social attitudes endure towards people with dementia which lead to negative stereotyping, loss of rights, stigma and social isolation.

Second, because health policy, at least in Australia, has yet to embrace dementia as a chronic disease, and instead treats dementia as a natural part of ageing.

I believe these two thoughts are closely linked. If there is not a positive approach to reducing the future numbers of people with dementia and a belief that that is possible, what grounds are there for hope? Equally, if there is not a better understanding of the approaches available to better care for dementia in the primary and acute care systems, what hope is there of reducing the negativity that pervades societal attitudes to dementia?

Having given you a sense of my conclusions I will talk about.

First, the framework within which we should present the development of dementia policy

Secondly, the evidence base for our revolution.

Thirdly, the critical importance of communications and the use of social media.

If Australian experience is anything to go by, it will take an enormous effort to persuade decision makers to adopt the long term view necessary to fight dementia. We need a social movement to change things.

It is the communication of ideas that in Australia is at least as important as the ideas themselves.

## SO WHAT SHOULD OUR NEW PARADIGM BE IN THE DEVELOPMENT OF DEMENTIA POLICY?

I think we have the building blocks for a revolution in dementia policy.

In Australia we know that a good evidence base works. The 2003 report commissioned by Alzheimer's Australia from Access Economics "The Dementia Epidemic: Economic and Social Impact and Positive strategies for Australia" was seminal in laying the foundation for the 2005 Dementia Initiative – Making Dementia a National Health Priority until \$320 million additional funding.

Other countries have since adopted the policy logic of the need to make dementia a priority to achieve nationally coordinated action. The focus and scope of these different initiatives has varied – in some cases the priority has been services, in others on early diagnosis and research.

The point is that we know what to do. And the elements of the approaches being adopted world wide can be reduced to nothing more than the public health framework that has worked well for other chronic diseases including cancer, heart, diabetes and others.

The framework we need is one that recognises the importance of:

- Information and awareness in promoting understanding of dementia
- Timely diagnosis to maximise the potential for care and planning legal and financial matters
- Support and care that maximises quality of life for the individual
- Promoting an understanding that changes in lifestyle may enable a person to reduce their risk of dementia
- Investment in research to better understand the causes of dementia and ways to slow progression and prevent dementia

Over the last ten years many Alzheimer's organisations have spent a great deal of time developing the evidence base for the need for action in each of these areas. So let's look at what that means in terms of a public health framework.

## AWARENESS AND UNDERSTANDING

Market research in Australia and elsewhere suggests there remains limited understanding about the symptoms of dementia beyond memory loss, for example, that it can affect younger people, that it is a terminal disease, that the symptoms develop decades before diagnosis or that lifestyle may offer some the possibility of risk reduction.

We do know that in Australia fear of dementia is second only to cancer and among people over the age of 50 it is the most feared disease. But this has not galvanised governments or the community to take action through research to beat the condition the way we have other chronic diseases.

There is also a need for greater awareness and understanding of the legal rights of people with dementia and their family carers.

Loss of capacity should not mean loss of rights, dignity or entitlements. People with dementia should be able to maintain their autonomy and self-determination for as long as possible and to be involved in supported decision making over their health care. However the evidence is that this is often not the case.

## TIMELY DIAGNOSIS

The major report released by Alzheimer's Disease International and prepared by the Institute of Psychiatry, Kings College London, that was released in September last year found that in high income countries only 20-50% of people living with dementia are recognised and documented in primary care. This means that up to 80% of people with dementia have not yet received a diagnosis.

In Australia we released a publication, Timely Diagnosis of Dementia: Can we do better? that reported that on average it takes 3.1 years from first symptoms of dementia to diagnosis. The publication went on to identify a wide range of barriers to timely diagnosis and possible strategies to address them including financial incentives, training, use of practice nurses and making the family carer a partner with the practitioners. People with dementia and their family carers in Australia have been expressing concerns about poor delays in diagnosis for years. The arguments have gained no traction with successive health ministers.

The years spent between first noticing symptoms and receiving a diagnosis are lost years and a time of worry, concern and uncertainty. A diagnosis of dementia may come as a relief because the family finally know what is wrong.

## SUPPORT AND CARE

Thinking about support and care starts with the recognition that even in developed countries it is the family carers who provide the care – about 70% in my country. Well designed aged care systems are fundamental to achieving the aim of enabling people to stay at home for as long as possible.

Recommendations for the reform of the aged care system that are before Government in Australia include:

- First, an entitlement to services based on an assessed need.
- Secondly, access to information to consumers and provision for link workers to guide consumers through the system.
- Thirdly, a priority for community services and especially flexible respite to better support the carer.
- Fourthly the development of outcome standards in residential care.
- Fifthly, a commitment to consumer directed models of care to empower consumers to take decisions on the services they need.
- Sixthly, user charges that balance the requirement for the system to be sustainable with equitable access.
- Lastly, access to end of life care, advance care planning and palliative care.

We support the architecture of the reforms that have been recommended by the Productivity Commission, the Government's independent economics advisory agency.

But a good aged care system is not enough to ensure good quality dementia care if it does not recognise the special needs of those with dementia. This is something we have to battle for in Australia even though dementia is the core business of aged care and is one of the most disabling of all conditions among older people and a major cause of institutionalisation.

Our Minister for Mental Health and Ageing has said a number of times that aged care reform that does not have a dementia response at its heart will not be successful. To that end we are advocating for:

- A funding model which recognises the extra costs of dementia care
- Expanded community care and particularly respite care that is appropriate for people with dementia
- Greater recognition of the importance of culturally appropriate dementia care
- Services for people with younger onset dementia
- Coordination of the aged care and mental health systems to address the needs of individuals with behavioural and psychological symptoms of dementia.

Alzheimer's Australia has long advocated for consumer directed models of care and we are pleased that these ideas are being included in the discussions of reform of the aged care system in Australia.

Many of you will be familiar with the concept but it has only recently been introduced into aged care in Australia and then in a modest way.

Consumer directed care describes the continuum of choice and consumer involvement on a number of dimensions of care including care planning, budget holding and service delivery.

For consumers the outcome should mean that they can determine what services they need, who should provide them and when and where they are provided. And for the current generation of older people and people with dementia in Australia it seems the inclination is to prefer budget holding approaches to cash.

By empowering the consumer, perhaps the dream of person centred care will become a reality.

## ACUTE CARE

**In acute care there is evidence in Australia as there is internationally that people with dementia are receiving poor quality care in hospitals and that poor quality care is leading to worse outcomes and longer stays. This in Australia is a relatively neglected issue. About 37% of Australian patients in hospitals are over the age of 65. Many of these have some form of cognitive impairment ranging from mild cognitive impairment to delirium and dementia. A recent report indicated that amongst people in hospitals over the age of 65, the rate of cognitive impairment was approximately 45%.**

The costs associated with poor quality dementia care will become an increasing problem for the hospital system, with a projection of hospitalisations of individuals with dementia quadrupling over the next 25 years due to population ageing. In Australia and in the UK there are consumer surveys and anecdotal reports conveying consumer concerns about the quality of care in hospitals. These centre on concerns about the lack of understanding of dementia of hospital staff, assistance with eating and drinking, person-centred care, recognition of dementia and opportunities for social interaction.

International studies and some Australian research has shown that people with dementia stay longer in hospitals than people without dementia, even after accounting for their principal reason for admission and procedure received. Due to their additional time in hospital, people with dementia are put at greater risk of hazards and poor outcomes. The policy conclusion seems to be that patients with dementia in hospital may be more appropriately treated in alternative settings and that the length of stay for patients with dementia may be reduced through the provision of more appropriate services in the community.

Within hospitals there is a need to better identify people with cognitive impairment, train hospital staff and coordinate care.

## PREVENTIVE HEALTH

### Preventive health and dementia risk reduction is an area where views differ.

In 2010 the National Institute of Health in the US released a report that suggested that there is not enough rigorous scientific evidence to support any definitive methods of preventing dementia. They acknowledged that there have been small studies that have suggested ways to reduce the risk of dementia but suggestion caution in the interpretation of these results until there have been more large-scale long-term studies. They expressed uncertainty about the direction of the relationship. "are people able to stay mentally sharp because they are physically active and socially engaged or are they simply more likely to stay physically active and socially engaged because they are mentally sharp"

Alzheimer's Australia takes a different view. We consider that there is now sufficient evidence to support the view that lifestyle changes may reduce the risk of dementia for some people. For example, there is now clear evidence that at least vascular dementia has the same risk factors as heart disease. Even without a clear causal link there is no harm in advocating for healthier lifestyles that may have a positive impact on brain health. This would cost little, risk no harm and may do some good while we await more positive outcomes from medical research.

Market research commissioned by Alzheimer's Australia demonstrates that 50% of Australians are unaware that they may be able to reduce their risk of dementia. Even among those who are aware there is something they can do to reduce risk, approximately 60% are not aware of the potential benefits of reducing high blood pressure, cholesterol and avoiding head injuries.

Alzheimer's Australia has developed and successfully

implemented the first stage of the Mind Your Mind ® public education program which provides information on ways to reduce risk for dementia. Funding is needed to roll out the program on a national scale.

We have built on this with the Brainy App

In November 2011, Alzheimer's Australia, in partnership with the Bupa Health Foundation, launched a smartphone and tablet application, BrainyApp.

BrainyApp is an app that aims to increase the awareness of dementia risk factors, particularly the association between heart health and brain health, while providing a personalised tool to help drive positive behavioural change.

We are thrilled with the immediate success of BrainyApp There have now been over 170,000 downloads of BrainyApp in 82 countries..

BrainyApp is currently only available for Apple devices – iPhone, iPad and iPod touch – but due to its great success we now have plans to launch an Android version The policy objective is to make the link between physical and brain health in government public health campaigns that address in cardiovascular disease, diabetes, obesity and smoking.

## RESEARCH

**The picture in medical research in Australia and worldwide is depressing although there has been some limited increase in funding for dementia research in recent years.**

In Australia we spend about \$6 billion a year on dementia in direct health costs and projections suggest dementia will become the third greatest source of health and residential aged care spending within two decades and the largest by 2060. Dementia research in Australia is grossly underfunded in relation to health and care costs, disability burden and prevalence compared to other chronic diseases. In the 2010-11 financial year, National Health and Medical Research Council research funding for chronic diseases was \$144 million for cancer, \$97.4 million for research on cardiovascular disease, \$63.1 million for diabetes. Alzheimer's disease and other types of dementias received only \$19.3 million.

We know that the impact of findings from dementia research could be very great. If the onset of Alzheimer's disease could be delayed by five years.

Meanwhile in Australia we invest less than 0.5 per cent of the cost of dementia each year.

## SO WHERE NOW?

**I believe in the Australian context the power of advocacy will come not just from the logic of the argument important though that is but from the effectiveness with which we get our messages across through branding and communications strategies.**

What we need is still greater passion in telling the stories of people living with dementia. And to do that more effective communication to overcome the negativity that pervades the politics of dementia and ageing more generally.

## MEDIA AND COMMUNICATIONS

**As I reflect on my time at Alzheimer's Australia since 2000 it seems to me that we have made great progress in accumulating the intellectual capital necessary to inform advocacy, empowering people with dementia to self advocate and getting the Dementia Initiative into place.**

We have come a long way in getting our message across from 2000 when in retrospect I believe we were almost apologetic for raising the issue rather than assertive.

The termination of the Dementia Initiative in the 2011 budget shattered our confidence that Governments would build on that platform. The funding of about \$170 million in a year seems secure for now but not the commitment to plan for the future.

This has been compounded over the last 4 years by the successive disappointments in failing to get dementia recognised in the health and hospital, primary care and preventive health reforms. So we formed the view that we needed to tell our story which much greater effect.

And to make the centre piece of that effort telling the stories of people with dementia and their family carers.

With that in mind we brought together two separate but related strategies with a view to promoting a social movement namely:

- A marketing and branding strategy
- A Fight dementia campaign

Over a period of nearly 18 months we have worked with Interbrand, a major international brand consultancy, on a marketing and branding strategy.

We launched the new brand on 13 October when we marched for the first time on Parliament house with 500 carers and people with dementia from across Australia. This was a turning point in the life of our organisation and something that has motivated many people because "We are doing something"

The advice we gave Interbrand early in the process was that we wanted to let off "A bloody great explosion" given what we perceive as a lack of understanding and support for the issue of dementia. The resulting strategy is to fight dementia. And by that I mean to beat it in the way that as a society we tackled cancer and heart disease in the last 50 years. Our brand essence is to shine through.

Apart from the march the strategies we have adopted have been innovative and quite different from anything we have done before including:

- The play on words that is possible with the new brand
- Fight Alzheimer's Save Australia
- Understand Alzheimer's Educate Australia
- Stop Alzheimer's Go Australia
- Linking the innovative use of the website at Christmas and New Years Day in the telling of consumer stories to social media.
- Active use of social media through Facebook, YouTube and Twitter with surprising results in attracting younger people
- Leadership by a President, Ita Buttrose, a high profile Australian who is a media personality and accomplished journalist. Ita has experience in public health education campaigns and a passionate interest in health and ageing issues.
- Innovative use of the website through an electronic advent calendar last Christmas with people with dementia telling their stories
- And on 14th February – Valentines Day for the unromantic – hearts were sent to the Prime Minister and other Ministers and Opposition spokespeople urging them to "Pop the question this Valentine's Day" "What would you do if your loved one did not recognise you' and to get action on dementia in the May Budget. The development of television adverts using paid advertising in a modest way for the first time.

It is hard to put outcomes on this activity yet. It is significant that we now have 38 Federal Parliamentary Members and Senators signed up as champions since last September. The media audience generated by the march was 7.6 million and advertising equivalent of the march and initial campaign activity was many times the cost.

Our estimate is that over 5000 Valentines Day cards arrived in the offices of our political leaders – the Leader of the Opposition has already responded.

We have successfully linked the campaign and the branding to our budget submission and fight dementia campaign and clear identification of consumer priorities in what we are arguing for. We have I think the best campaign document and supporting brief that we have ever had – all of which you can find at [campaign.fightdementia.org.au](http://campaign.fightdementia.org.au)

So we have a state of excitement and passion. The task of course will be to sustain it and to get results in either the 2012 budget, 2013 budget or failing all of that the 2013 election. It is indeed a long road.

## CONCLUSION

**We have spent the last ten years gathering the evidence on the social and economic impact of dementia.**

The experience of the first national dementia plans around the world gives us the confidence we know the priorities for action – awareness, early diagnosis, care and support, dementia risk reduction and investment in research.

Within that framework we need to establish dementia as a priority and a commitment to plan ahead with additional funding. We need to empower consumers through consumer directed care and building a social movement.

I am convinced we know what it is we need to do to get a better quality of life for people with dementia and their carers. It is not just funding, it is also the way services are provided. Hence the emphasis I have given to consumer directed care.

Lastly, we must communicate the urgent need for action in health and aged care policy with greater sophistication, passion and assertiveness than we have ever done before.

In that way by being positive we will achieve a world which is much more dementia friendly and which recognises dementia as a major chronic disease that needs to be addressed through a public health framework.



# ALZHEIMER'S AUSTRALIA PUBLICATIONS

## Quality Dementia Care Series

1. Practice in Residential Aged Care Facilities, for all Staff
2. Practice for Managers in Residential Aged Care Facilities
3. Nurturing the Heart: creativity, art therapy and dementia
4. Understanding Younger Onset Dementia
5. Younger Onset Dementia, a practical guide
6. Understanding Dementia Care and Sexuality in Residential Facilities
7. No time like the present: the importance of a timely dementia diagnosis
22. Consumer Involvement in Dementia Research  
September 2010
23. Planning for the End of Life for People with Dementia  
Part 1, March 2011 Part 2, May 2011
24. Timely Diagnosis of Dementia: Can we do better?  
September 2011
25. National Strategies to Address Dementia, October 2011
26. Evaluation of NHMRC data on the funding of dementia research in Australia, March 2012

## Papers

1. Dementia: A Major Health Problem for Australia.  
September 2001
2. Quality Dementia Care, February 2003
3. Dementia Care and the Built Environment, June 2004
4. Dementia Terminology Framework. December 2004
5. Legal Planning and Dementia. April 2005
6. Dementia: Can It Be Prevented? August 2005  
(superceded by paper 13)
7. Palliative Care and Dementia. February 2006
8. Decision Making in Advance: Reducing Barriers and  
Improving Access to Advanced Directives for People with  
Dementia. May 2006
9. 100 Years of Alzheimer's: Towards a World without  
Dementia. August 2006
10. Early Diagnosis of Dementia. March 2007
11. Consumer-Directed Care – A Way to Empower Consumers?  
May 2007
12. Dementia: A Major Health Problem for Indigenous People.  
August 2007.
13. Dementia Risk Reduction: The Evidence. September 2007
14. Dementia Risk Reduction: What do Australians know?  
September 2008
15. Dementia, Lesbians and Gay Men. November 2009
16. Australian Dementia Research: current status,  
future directions? June 2008
17. Respite Care for People Living with Dementia. May 2009
18. Dementia: Facing the Epidemic. Presentation by Professor  
Constantine Lyketsos. September 2009
19. Dementia: Evolution or Revolution? Presentation by  
Glenn Rees. June 2010
20. Ethical Issues and Decision-Making in Dementia Care.  
Presentation by Dr Julian Hughes. June 2010
21. Towards a National Dementia Preventative Health Strategy.  
August 2010
22. Consumer Involvement in Dementia Research  
September 2010
23. Planning for the End of Life for People with Dementia  
Part 1, March 2011 Part 2, May 2011
24. Timely Diagnosis of Dementia: Can we do better?  
September 2011
25. National Strategies to Address Dementia, October 2011
26. Evaluation of NHMRC data on the funding of dementia  
research in Australia, March 2012

## Reports commissioned from Access Economics

The Dementia Epidemic: Economic Impact and Positive Solutions for Australia, March 2003

Delaying the Onset of Alzheimer's Disease: Projections and Issues, August 2004

Dementia Estimates and Projections: Australian States and Territories, February 2005

Dementia in the Asia Pacific Region: The Epidemic is Here, September 2006

Dementia Prevalence and Incidence Among Australian's Who Do Not Speak English at Home, November 2006

Making choices: Future dementia care: projections, problems and preferences, April 2009

Keeping dementia front of mind: incidence and prevalence 2009-2050, August 2009

Caring places: planning for aged care and dementia 2010-2050. July 2010

Dementia Across Australia 2010-2050. September 2011

## Other Papers

Dementia Research: A Vision for Australia September 2004

National Consumer Summit on Dementia Communique, October 2005

Mind Your Mind: A Users Guide to Dementia Risk Reduction 2006

Beginning the Conversation: Addressing Dementia in Aboriginal and Torres Strait Islander Communities, November 2006

National Dementia Manifesto 2007-2010

Dementia: A Major Health Problem for Indigenous People August 2007

In Our Own Words, Younger Onset Dementia, February 2009

National Consumer Summit Younger Onset Dementia Communique, February 2009

Dementia: Facing the Epidemic. A vision for a world class dementia care system. September 2009

These documents and others available on  
[www.alzheimers.org.au](http://www.alzheimers.org.au)

**VISIT THE ALZHEIMER'S AUSTRALIA WEBSITE AT  
WWW.FIGHTDEMENTIA.ORG.AU**

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