



Dementia and National Policy: A Time for Revolution?

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I am grateful to the organisers of this conference and particularly Suzanne Cahill and Caroline Forsyth for inviting me and looking after me so well. There are all too few opportunities to share experiences for us in Australia.

I have taken the opportunity to reflect on where we have come from in thinking about dementia in the last 30 years.

I have been privileged to play a part in Australia in the strategic directions set in aged care in the 1980s as Chair of the Nursing Homes and Hostels review. And then subsequently, I played a part in the implementation of those strategies. I have been CEO of Alzheimer's Australia since 2000.

In the mid 1980s, in Australia, there was a very limited understanding of dementia or of the steps that should be taken to provide good quality care. The best we could do in my review was to recommend dementia grants in low care residential hostels to promote good design and better care

Today we can point to enormous change even though as I will argue there is a need for revolution in the way that we think about dementia and advocate for action to tackle it.

I have come to this view 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 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, recent Australian policy developments

Secondly, the need for new thinking in the development of dementia policy.

Thirdly, the importance of engaging the political level and the wider community in dementia care through innovative communication and media strategies.

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.

I will suggest it is the communication of ideas that in Australia is at least as important as the ideas themselves.

Before I get too earnest wearing my policy hat, let me illustrate what I want to say in a slightly light-hearted way.

These are the three logos of Alzheimer's Australia since 2000. On view is the progression from the warm carer mentality with a vacant figure – presumably a person with dementia. A slightly more modern depiction with a new tag line living with dementia but with no brand essence or marketing strategy to go with it. And our new brand that we have just introduced and about which I will say more later.

Ten years ago I could not have imagined that Alzheimer's Australia would have been positioned psychologically or intellectually to mount a march on Parliament house.

The language and the look and the feel of our organisation is fast changing. Our journey has been one of developing intellectual capital. Now we have our arsenal the challenge is to communicate it in ways that would have been inconceivable even three years ago.

Australian experience

The Dementia Initiative in the 2005 Budget was a landmark for people living with dementia, both people with dementia and their families and carers. Australia was the first country to acknowledge the economic and social impact of dementia and to begin the process of planning for the epidemic.

And \$320 million was provided in additional funding over 5 years –a number that has grown to about \$180 million per annum as a consequence of the largest element – high care community dementia care packages worth about \$48000 per annum - being linked to the ageing of the population.

The Independent Evaluation of the Initiative is consistent with the views of consumers, namely that it achieved much of its promise and shown positive returns on the investment made by the Australian Government.

From a consumer perspective the highlights of the Dementia Initiative have been:

- The opportunity to improve access to specialist dementia services and demonstrate the potential of greater choice for consumers for access to community care packages
- The increased community engagement through community grants and sector development grants and the community education activities made possible

through improved funding for the National Dementia Support Program (NDSP) administered by Alzheimer's Australia.

- The much needed funding increases in dementia care research through the three Dementia Collaborative Research Centres and dementia research grants, which have increased research capacity, promoted collaboration, attracted young researchers into the field of dementia care and positioned dementia researchers to apply for NHMRC and other major grants.
- The opportunity after a slow start to improve the quality of dementia care through the Dementia Behaviour Management Advisory Services.
- The expanded opportunities for workforce education and training through Dementia Care Essentials and the Dementia Training Study Centres.
- The improved access to support for people with dementia and their family carers through targeted resources and improved funding through the NDSP.

However, as the Evaluation makes clear the Dementia Initiative fell short of the action needed to combat the dementia epidemic in key areas. These include the lack of a communication strategy or action on primary care.

Given the bipartisan support for the Initiative we assumed that it would be the platform on which to build for the future. This proved to be an entirely wrong assumption because the current Government terminated the Initiative in the May 2011 budget.

I should add that the funding, at least for the foreseeable future, will continue for the various elements of the Initiative. But we have lost the political focus to plan ahead, the guaranteed funding and the potential capacity to address emerging priorities. The Initiative was the victim of structural changes within the Department but the consequence was a blow to the hopes of people living with dementia for whom the Initiative held out the prospect of political priority.

The positive of this unexpected development is that it has shattered our confidence that we had developed as a consequence of the 2005 landmark decision. We have the opportunity to think in a more coherent way about what we want from the future and free of the constraint of the Initiative which was framed in the context of aged care to the neglect of many important priorities in health.

So what should our new paradigm be in the development of dementia policy?

Dementia needs to be acknowledged as a major chronic disease that needs to be addressed through both the health and aged care system. If the public health framework developed for other chronic diseases is good enough for cancer, heart, diabetes and others then it should be good enough for dementia.

In Australia we have had some success in engaging the aged care system in providing better care for people with dementia since the late 1980s. The sad

consequence seems to be that dementia has been pushed out of the medical system and considered to be more a matter of discreet warehousing in aged care.

But while the problem of dementia has been recognised in aged care there has been an assumption that the mainstream aged care system will address issues of concern to people with dementia.

It has been hard for example to get recognition of the extra costs of dementia care and the need to train workers in psycho-social care before resort to medical and physical restraint.

There has been scant recognition of the need for respite care that is both flexible enough to meet the needs of the family carer and also provides interest and activities for person with dementia.

Again it has been problematic in Australia to get recognition of the extra funding needed to care for those with severe BPSD (behavioural and psychological symptoms of dementia), in part at least because these people fall between the aged care system on the one hand and the mental health system on the other.

And of course there are no age appropriate services for younger people with dementia.

But the biggest policy disappointment has been the failure of those responsible for health policy to respond to pleas for timely diagnosis, safer hospitals, dementia risk reduction and investment in research.

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

Awareness and Understanding

I will have more to say to say on awareness but in the Australian context market research suggests there remains limited understanding of the symptoms of dementia beyond memory loss, that it can affect younger people, that it is a terminal disease, that the symptoms develop decades before diagnosis or that lifestyle changes may offer for some the possibility of risk reduction.

We do know that fear of dementia is second only to cancer 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 this is often not the case.

We need to understand better the ethical decision areas of most concern to consumers, how well current law protects the individual rights of people with dementia and the strategies to address the concerns and problems identified.

In this area it may be that Australia has a good deal to learn from legislation overseas.

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.

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.

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.

Support and care

The Australian Prime Minister has committed to reform of aged care in this term of Government. As part of this commitment, the Productivity Commission- the Australian Government's independent research and advisory body was asked to produce report on aged care with a set of recommendations for reform. This report on Caring for Older Australians has set the scene for significant reform of Aged care in Australia. The question of course is whether it will be affordable as disabilities services, mental health and dental health compete for scarce dollars.

The principle elements of the reforms are

- First, expanded access to services based on an assessed 'entitlement to services'. That word entitlement is still to be well defined, but it really means that services will no longer be rationed.
- Secondly, increased access to community care by removing the link between care and accommodation and expanding community care packages.
- Thirdly, improved access to information and assessment through a gateway designed to bring together information and assessment to enable consumers to know where they should go more easily to gain information about services and to be assessed for services.
- Fourthly, a commitment to consumer directed models of care to better meet consumer needs through flexible services.
- Fifthly, changes to the user pay system to create a more sustainable aged care system.
- Improved access to end of life care, advance care planning and palliative care.

There is no recommendation in the report that addresses dementia even though dementia is the core business of aged care. Yet in Australia the majority of residents in aged care have dementia; it is the most disabling of all conditions among older people and it is one of the main causes of institutionalisation.

Alzheimer's Australia is 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. The differences between need for and use of respite on the part of dementia carers and all carers are striking. Dementia carers are:
 - about half as likely to say that they had no need and had not used respite;
 - 50% more likely to need and have used respite; and
 - more than 10 times more likely to say they need respite but had not used it.

there are two dementia carers who need but have not used respite care for every three who have used it.
- Greater recognition of the importance of culturally appropriate dementia care

- Individuals with younger onset dementia to have access to care that meets their needs
- Coordination of the aged care and mental health systems to address the needs of individuals with behavioural and psychological symptoms of dementia.

I should add that Alzheimer's Australia has long advocated for consumer directed models of care and we are strongly supportive of the recommendations made by the Productivity Commission in respect of CDC. In my view person centred care will remain a distant dream in the absence of consumer empowerment and choice.

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.

Going across these three dimensions and the various types of choices that can be available under each means that consumer directed care can mean many different things to different people.

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.

The one exception in my view is respite care where the flexibility needed may require cash or vouchers and the Productivity Commission have recommended a trial and evaluation of cash in respite care.

We are hopeful that the final reform package will set out to improve dementia care as part of the aged care reform. The Minister for Mental Health and Ageing has a good understanding of dementia and has publicly said that aged care reform that does not have a dementia response at its heart will not be successful.

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 issue is important as there are over 260,000 people with Dementia in Australia today and a projection of nearly a million by 2050.

Given that in 2009-2010 54% of people in hospitals were over the age of 55 it is likely that there is a large number of people in hospitals who have some form of cognitive impairment ranging from mild cognitive impairment, delirium and dementia.

A recent report indicated that amongst older people in hospitals, the rate of cognitive impairment was approximately 45%.

The costs associated with poor quality dementia care is only going to 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 lengths of stay for patients with dementia may be reduced through the provision of more appropriate services in the community.

Preventive health

Preventive health and dementia risk reduction is an area where views differ. The Productivity Commission in its final report on Caring for Older Australians acknowledges the potential benefits and cost effectiveness of preventative health and wellness programs in the context of dementia but raises concerns about the evidence base for some of these Initiatives: "Given the claims about the potential cost-effectiveness of prevention and early intervention measures, there is a need to know more about the effectiveness of different interventions in preventing or reducing the likelihood of particular outcomes" (Productivity Commission 2011, p 439) The Commission suggests that research with a focus on prevention and early intervention for older people could be conducted within the new National Health Promotion and Prevention Agency.

This seems unlikely in the short term as preventive health in Australia is dominated by three priorities in Australia – smoking, excessive alcohol consumption and obesity and there has been no effort to link these efforts to brain health

Last year 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.

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. Among those who are aware that it is possible to reduce the risk of dementia, there is limited understanding of the full range of potentially positive changes in health habits. For example, even among those who are aware there is something they can do to reduce risk, approximately 60% of Australians 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.

Information about the effects of a healthy lifestyle on brain health should also be included in existing government public health campaigns that address behaviours and diseases that are linked to dementia such as cardiovascular disease, diabetes, obesity and smoking. This would cost little, risk no harm and may do some good while we await more positive outcomes from medical research.

Research

The picture in medical research is even more depressing in the lack of priority given to dementia although in recent times there has been more acknowledgement and a little more funding for dementia research in Australia.

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 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 prizes from dementia research could be very great. If the onset of Alzheimer's disease could be delayed by five years, the numbers of people with dementia would be halved (between 2000 and 2040).

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

So where now?

We now have a Minister responsible for ageing in Cabinet. The last time that was the case was in the mid 1980s and we got aged care reform implemented on a major scale. But the rivers of gold have dried up even in Australia. And the last decade suggests that aged care is far from the top of political minds.

We know what needs to be done and have done for some years. And there is a reasonable evidence basis to support it. With all respect to policy makers it seems to me the elements we need now are passion and much more effective communication.

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 another source - namely the way we communicate in our advocacy.

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 and in particular 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. 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 preventative health reforms. So we formed the view that we needed to tell our story with 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 on dementia, namely:

- A marketing and branding strategy
- A Fight dementia campaign

Over a period of nearly 18 months we have worked with Interbrand on a marketing and branding strategy. Interbrand are a multi national company who have done much of the work for us pro bono. The starting point was an ambition by 2020 to be a top ten charity.

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 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 piece 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, not in a political sense but to beat it in a 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
- Active use of social media through Facebook, YouTube.
- Leadership by a President, Ita Buttrose, with a high profile Australian who is a media personality and accomplished journalist. Ita has experience in public health education campaigns and a long held 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 for each of the 12 days. There was similar media activity around New Years day expressing the wishes of carers of people with dementia and urging politicians and the wider community to make 2012 a year to remember.
- And on 14th February next month – Valentines Day for the unromantic – hearts will be sent to the Prime Minister and other Ministers and Opposition spokespeople urging them to “Pop the question this Valentine’s Day” 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).

Again much of this has only been possible because of generous pro assistance in social media from Clemenger and their Australian company Porter Novelli

It is hard to put outcomes on this activity yet. It is significant that we now have 35 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.

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 it is the best campaign document and supporting brief that we have ever had.

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.

Conclusion

Australia has by most world standards a good aged care system and good care for people with dementia. That system is however overdue for reform and we are fighting hard to make dementia and the quality of care a major issue.

It remains a disappointment that those responsible for health policy have been so lacking in interest in key issues of concern to consumers such as timely diagnosis, acute care, dementia risk reduction and investment in dementia research. Perhaps it is still the case that for many dementia is still seen as a natural part of ageing.

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.

More than anything, I think those of us who have the privilege to be part of the advocacy with and for people with dementia need to have greater passion and assertiveness in the way we deliver our message. And, to do that with greater sophistication using branding and social media to achieve our objectives.

Thank you