
Dementia: Evolution or Revolution?

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Evolution or Revolution?

Alzheimer's Australia greatly values its partnership with the Hammond Group and I am grateful to the organisers of this Hammond Conference for giving me this opportunity to speak.

In reflecting on the theme of this Conference and whether we need to think about dementia in different ways I have tried to overcome any biases I have.

I played a part in the Aged Care Reforms of the 1980s and have been CEO of Alzheimer's Australia for ten years.

Moreover, an advocate in my view has to be positive however depressing the immediate scene maybe. This is because people need hope and because Governments do not take kindly to criticism.

Having said that, my feeling is that there has been significant progress in addressing the issues that face people living with dementia over the last 30 years.

Nonetheless, I think the time has come for revolution in the way we think about dementia in the advocacy of Alzheimer's Australia for two main reasons.

First, there are pervasive negative social attitudes towards people with dementia which lead to negative stereotyping, stigma and social isolation.

Second, health policy has yet to embrace dementia as a chronic disease, and instead treats dementia as a normal consequence of ageing.

The two thoughts are linked. If there is not a positive approach to reducing the future numbers of people with dementia and 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 let me explain how I have arrived at them.

First, I will identify the major elements of progress in respect of dementia in the last 30 years.

Secondly, I will give my view of the unfinished business in health policy in respect of dementia.

Thirdly, I will suggest a few ideas on how we get the revolution to happen.

What has changed?

So what has changed in respect of stigma, policy, services and dementia care since 1980?

Stigma

The willingness of people with dementia to self advocate and to speak out in the last ten years at the Summits organised at Parliament House by Alzheimers Australia, in the media and at conferences and seminars is an important first step in being socially inclusive and demonstrating that life goes on after a diagnosis of dementia.

My view is that the vast increase in information on dementia and good media coverage in recent years, this has done little to diminish the stigma and social isolation experienced by people living with dementia.

The literature on the negative stereo-typing of people with dementia suggests that the stigma associated with dementia may lead to delays in diagnosis, reluctance to access dementia care services as well as social isolation.^{1 2}

Quotes from people with dementia who have experienced stigma or negative stereo-typing abound in the literature.³ Individuals with dementia and family carers who are involved in advocacy with Alzheimer's Australia report that stigma and social isolation are alive and well and that a high priority for consumer advocates is the need for strategies to promote greater awareness and understanding of dementia.⁴

Daphne Wallace worked in psychiatry for older people in the National Health Service in the UK for 25 years. When she was just 65 years old, Daphne was diagnosed with vascular dementia. In recounting her experiences, she said this: "Nowadays, people with a diagnosis with cancer are not usually shunned or feared. Unfortunately a diagnosis of dementia can evoke similar reactions to those of cancer in the past. In the developed world in particular, the importance of cognitive ability and an intellectual emphasis on life, can cause neglect of the abilities and needs of those with dementia".⁵

In a similar vein, Christine Boden in her book *Who Will I Be When I Die?* said: "If I were to die of cancer I would still be the real me, the one I know, the one my family and friends know – the mother of my three girls and member of my Church family. When I die of Alzheimer's, who will I be when I die?"⁶

Policy

In terms of policy the Commonwealth has assumed the main responsibility for dementia care – although sadly not for younger people. This division in responsibilities was not as clear at the beginning of the 1980s even though the closure of state mental health facilities had increasingly meant that costs were shifted to Commonwealth funded nursing homes.⁷

The emergent nature of policy discussion in the early 1980s can be seen in the work of a House of Representatives Inquiry into Home Care and Accommodation for the Aged. In the words of Dr Anna Howe "dementia came to be recognised as a problem, but the nature of the problem was only beginning to be understood and no solutions were advanced".⁸

From my own experience in the Nursing Homes and Hostels Review in the mid 1980's I know that we struggled with what to recommend in respect of dementia. In the end we recommended that "recurrent funding should be made available for dementia grants in hostels."⁹

There was a positive industry response to the dementia grants. My experience at that time and since has served to reinforce my belief that designated funding is necessary to achieve appropriate dementia care and to recognise the additional costs involved.

The focus on dementia in the early 1990s in the Mid Term Review of the Aged Care Reform Strategy led to the release of the *Putting the Pieces Together: A National Action Plan for Dementia Care* in 1992. The Plan achieved a good deal in promoting demonstration projects, training, research consultancies and addressing gaps in existing programs.

Unfortunately, due to the change of Government in 1997, there was no consolidation of the Plan at the end of its 5 years lifespan.

In the last ten years there have been two significant developments.

First, there has been a partnership since 2000 between the Commonwealth Government and Alzheimer's Australia through the funding of the National Dementia Support Program. On the basis of this partnership, Alzheimer's Australia has been able to deliver an integrated suite of services and to develop intellectual capital that has contributed significantly to policy and program development.

Second, in the 2005 Budget, the Dementia Initiative was funded with an additional \$320 million over 5 years. This funding was used to introduce new Extended Aged Care at Home (Dementia) packages, training initiatives, dementia care research and the National Dementia Support Program.

This was a landmark decision for people living with dementia. An independent evaluation, which is not yet public, has shown the Initiative to be effective. This is certainly the view of Alzheimer's Australia.

Services

Since 1980 there have been significant improvements in service provision.

In the 80s there was a dearth of information about dementia and a lack of community based support, education for family carers and respite care. There were also significant consumer concerns about the provision of dementia care in residential services and the need for more and better staff training.

The family carers who founded Alzheimer's organisations at the State and Territory level in the early 1980s would I think be pleased with what has been achieved over the last 30 years in expanding dementia-friendly community care and residential services, while recognising that there is a great deal of unfinished business.

Importantly, there has been a significant expansion of community services, and in particular respite care. There has been in recent times an increasing recognition of the importance of social engagement and activities in the design of community based dementia services.

Nonetheless, the dominant feature of the dementia landscape is still residential care.

There has also been progress towards recognizing the need for specific designated funding in both residential and community care for dementia care. This has been seen in the new Aged Care Funding Instrument and EACH (D) which recognise the special issues that relate to behaviours and the cost associated with such care.

Quality Care

It was in 1979 that psycho-geriatrics first appeared as a topic on the Annual Conference of the Australian Association of Gerontology.¹⁰ From where I sat doing the review in the mid 1980s there was little evidence of the importance of psycho-social approaches in dementia care of the kind that Mike Bird and others have taught us to value today.

There have been many developments since the 1980s including the adoption of person centred care approaches, the work of Professor Brodaty on the benefits of coordinated carer support, the first Alzheimer's medications and the recognition of the importance of good design and assistive technology.

The Dementia Initiative has helped to promote quality dementia care through increased and sustained resources for training, access to advice for family carers and residential care providers through the Dementia Behaviour Management Advisory Services, the Dementia Training Study Centres at the tertiary level and the funding for dementia care research through the three Dementia Collaborative Research Centres.

Unfinished Business

There is unfinished business both in aged care and in health care.

Aged care

In aged care at long last there is the prospect of change. The Productivity Commission is approaching their Inquiry into aged care from the perspective of the needs of older people and how the aged care system should be designed to meet those needs.

It is also a positive development that the Australian Government and States and Territories with the exception of Victoria and Western Australia are committed to national funding of aged care.

The focus of the Final Report of the National Health and Hospital Reform Commission on increasing choice in aged care and the publication of the Productivity Commission in September 2008 of ***Trends in Aged Care Services: Some Implications*** encourage me to think that the scene is set for reforms that will lead to the flexibility in service provision necessary to enable the older person and their family and carers to choose the mix of community and residential care services that best meets their needs.

The recently announced commitment of the Australian Government to fund 1,200 consumer directed care packages and the increasing support for funding people rather than places give me hope that within a reasonable transition period of perhaps 8-10 years, Australian aged care could look very different.

And of course, it is not just a question of changing funding and program arrangements, but the cultures within which services are provided and the empowerment of older people to determine for themselves, if they wish, the services that best meet their needs and how and when they want them delivered.

In such a world, graduated care packages, mixes of community and residential care, respite care that caters for both the carer's need for a break and the need of the person with dementia for social engagement and activities of interest may become a realistic expectation of service delivery.

In relation to dementia, there are a number of specific proposals we will put to the Productivity Commission to enhance the choices available to people with dementia and the quality of their care. These will include:

- A behavioural supplement across all care packages to recognise the extra costs involved in supporting those who exhibit the Behavioural and Psychological Symptoms of Dementia.
- Dedicated funding and allocated residential places for those who have severe psychiatric and behavioural issues.
- Recognition of the special issues in respite care for those with dementia if their social isolation is to be reduced through meaningful activities and social engagement.
- Action directed at reducing the use of antipsychotics in residential care.

- Funding for knowledge translation activities that result in research evidence being translated into better practice.
- A greater emphasis on equitable provision of services for those communities at a particular disadvantage, and in particular CALD and Indigenous communities where awareness of dementia is often lower and stigma greater.
- A commitment by Government to expand the innovative component of the National Dementia Support Program.
- A commitment to expanding the Dementia Behavioural Management Advisory Services to address the management of BPSD

Alzheimer's Australia has commissioned Access Economics to compare projected supply of residential and community dementia care places with demand to 2050, and to examine the implications of various funding models. We expect this to be an important input to the Productivity Commission.

Health Policy

The deafening silence about dementia in the recent health reform process suggests we have a greater challenge in respect of health policy.

The response to cancer and polio in the last century was not to warehouse the patient but to beat the issue. We see none of that in current health policy in respect of dementia.

To the contrary, investment in dementia research is low. The National Health and Medical Research Council spends about \$22 million on dementia research. Cancer attracts nearly \$160 million, cardiovascular \$110 million and diabetes over \$60 million.¹¹

The proportion of medical research expenditure on dementia does not reflect the importance of dementia as a chronic disease in terms of its prevalence, disability burden and health and residential care costs. When these factors are taken into account, it becomes obvious that dementia research is severely underfunded.

The Dementia Initiative introduced additional investment in dementia care research. The need is for an urgent injection of investment in research in order to:

- Better understand the causes of dementia.
- Develop medical interventions that delay the onset of dementia.
- Identify those at most risk of developing dementia.
- Further develop the evidence base regarding dementia risk reduction.

There is also a need for health policy to address preventative strategies to reduce the incidence of dementia. Our market research shows that 50% of Australians are currently unaware that they may be able to reduce their risk of dementia.¹² Worse still, those that are aware have little understanding of the links between dementia and cardiovascular disease, high blood pressure and high cholesterol levels.

Given that 70,000 baby boomers will have dementia by 2020, it is high time that dementia risk reduction found its way into preventative health.¹³ Prevention programs for example, in respect of heart disease, diabetes, obesity and alcohol abuse should recognise not only the physical benefits of health prevention but also the benefits to brain health.

It would cost relatively little for a national public-awareness campaign around the **Mind your Mind**® program developed by Alzheimer's Australia to promote awareness of how the risk of dementia can be reduced through changes in lifestyle and behaviours.

We also need to address the accurate and timely diagnosis of dementia. Again, our market research shows that over 94% of Australians would go first to their GPs if concerned about their memories.¹⁴ However, there is ample evidence that many GPs have difficulty in diagnosing dementia and are reluctant to provide a diagnosis when there is no cure.¹⁵

There are no single or simple solutions to these complex issues. We have proposed to the Federal Health Minister that stakeholders including the Royal College of General Practitioners, the Australian New Zealand Society of Geriatric Medicine, the Australian Divisions of General Practice, the Royal College of Nursing Australia, and the Australian Practice Nurses Association among others should meet in the context of the Australian Government's reforms in primary care to:

- Assess the evidence base for timely diagnosis and ongoing management of dementia.
- Develop proposals that could be further developed for consideration.

Proposals to achieve effective primary healthcare diagnosis and treatment for dementia are likely to require adequate incentives and training for GPs and Practice Nurses to secure an appropriate response to those presenting with cognitive impairment. The objective is very simply to reduce the time from symptom presentation to diagnosis. This in turn will help with timely access to planning and care services, and may significantly reduce the uncertainty and distress experienced by individuals and their families.

It is also important that people diagnosed with dementia are referred to organisations such as Alzheimer's Australia to have access to counselling, community based support and advice on legal and driving issues.

Lastly, acute care remains an especially dangerous setting for people with dementia – and potentially more so for those whose dementia has not been formally diagnosed. Impaired mental status is the most commonly identified factor in patients who fall while in hospitals.¹⁶ It is difficult to provide adequate and effective care to treat other diseases when an individual has unrecognized cognitive impairment. For individuals who have been diagnosed, the focus on diagnosis and treatment of acute medical and/or surgical problems may lead to inadequate or inappropriate care.

A positive approach to dementia care begins with the recognition that a person with dementia is still a person. Many staff in acute care settings have not been exposed to 'person-centred' and other contemporary approaches to caring for people with dementia, or their families and carers.

Better outcomes for people with dementia as well as less burden on hospital staff could be achieved through:

- Minimising unnecessary and unwanted hospital admissions.
- Recognising the need for people with cognitive impairment to be supported and to feel secure.
- Improved hospital practices to better recognise cognitive impairment.

Younger Onset dementia

No catalogue of unfinished business would be complete without mention of younger onset dementia.

COAG have decided that the 15000 Australians with younger onset dementia should be the responsibility of disability services with the aged care system providing assessment and services where no other services are available.

Alzheimer's Australia has raised three concerns with Ministers.¹⁷

First, how is the disability sector going to gain an understanding of the care and support needs of people living with dementia?

Second, what resources are available to the sector to develop services appropriate for people with younger onset dementia?

Thirdly, what requirement is there on individual States and Territories to embrace younger people with dementia within the COAG initiative?

There is a significant risk of younger people with dementia being bounced between disability and aged care services. When disability services are no longer able to meet a younger person's needs due to the progression of dementia, will the person and their family carers then have to navigate a second unfamiliar system? Is there any possibility of a smooth and seamless service for this group?

I should acknowledge the important work Hammond is undertaking to develop an appropriate community and residential based model for the younger group at Horsley. I hope other services will follow their example.

The seeds of revolution

My conclusion is that the unfinished business requires revolution rather than evolution both in the implementation of what we already know and in new ways of thinking.

Having health care centre stage with extra funding was a positive in the budget. But the neglect of dementia including additional funding for the Dementia Initiative was a great disappointment.

More doctors, more beds, and more nurses alone will not solve issues around dementia. Instead we need a cultural shift in the way we approach dementia. If a revolution can deliver on consumer choice, better primary and acute care and on a health policy to reduce future numbers through research and risk reduction, then the top of our mountain may be within reach.

Systemic reform in areas like primary care is critical to achieve change. But we need to build on the elements of the Dementia Initiative to ensure that there is the capacity to promote change in the system.

The seeds of revolution rest in using the knowledge we have to make ambitious and positive steps forward in the field of dementia. The potential for the future includes:

- Providing a better quality of life for individuals with dementia by offering high quality dementia care
- Reducing isolation for individuals with dementia and their carers by eliminating negative stereotypes and promoting greater social inclusion
- Reducing the numbers of individuals with dementia through risk reduction and new medications.
- Delaying the onset of dementia by identifying those at most at risk

This potential will not be reached by continuing with the status quo. Dementia is one of the most feared chronic conditions, yet the policy and community response to dementia epidemic has largely been to carry on with business as usual through the aged care system, and residential care in particular.

What Alzheimer's Australia would like to see is a revolution in thinking from dementia as an inevitable part of ageing to a condition that we can beat through better dementia care and investment in research.

There needs to be a community and political response to the dementia epidemic that attempts to remove fear by investing in research and promoting better understanding of the condition and the possibilities for dementia risk reduction through mental, physical and social activity and reduced blood pressure and cholesterol.

Disability advocates have shown us the way. And the way is to ensure that older people and their families and carers are empowered to determine the support they need. Older people's organisations in Australia lag behind disability groups in their focus on rights and empowerment.

It may be the foot soldiers rather than the generals who are the key to change.

Alzheimer's Australia has advocated for consumer directed care for nearly ten years, primarily because we see that is the only way of making sense of philosophies such as person centred care. If the older person or their families have no voice, how is person centred care to be achieved?

Although the last 30 years have huge positives for people living with dementia we have a long way to go in changing societal attitudes and meeting the challenge of dementia head on.

Like Everest, dementia can be beaten. We know the best routes. It is time to push for the summit.

A few quotes to inspire us all. Thank you

Change is the law of life and those who look only to the past or present are certain to miss the future. **John F. Kennedy**

The ultimate end of all revolutionary social change is to establish the sanctity of human life, the dignity of man, the right of every human being to liberty and well-being. **Emma Goldman**

A revolution is an idea which has found its bayonets. **Napoleon Bonaparte**

Promise yourself to live your life as a revolution and not just a process of evolution. **Anthony J. D'Angelo,**

Revolutions always come around again. That's why they're called revolutions.
Terry Pratchett,

Endnotes

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