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DEMENTIA AND AGED CARE REFORM: A CONSUMER PERSPECTIVE

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I am grateful to IRR Conferences for giving me an opportunity to talk about dementia and aged care reform.

It is hard to get the balance right between excitement and gloom.

The Productivity Commission has put beyond doubt in their analysis the case for significant reform of aged care. The architecture for reform has been broadly supported by most consumer, provider, staff and professional bodies.

At the same time there is uncertainty because:

- Government has yet to indicate whether decisions will be taken in the 2012 or 2013 budget.
- It is uncertain whether reform will enjoy the bipartisan support so necessary given that the staged process of implementation will take place over many years.
- The global financial crisis continues to cast a long shadow over government expenditures.

The National Aged Care Alliance has strongly supported the need for significant reform and published on 9th February their blueprint for reform based on the principles and recommendations of the Productivity Commission.

The blue print is a comprehensive document and one which Alzheimer's Australia strongly supports. I commend it to you.

From the perspective of those living with dementia the important issues in aged care reform are to:

1. Ensure the focus of reform is on addressing the objective of enabling older people to stay home longer
2. Identify a new paradigm for addressing the dementia epidemic.
3. Developing a comprehensive, funded strategy to address dementia across the health and aged care system
4. Have a clear view about where to start in implementing reforms

The report of the Productivity Commission

The judgement of the Productivity Commission is that the current aged care system is not working well for consumers and is not sustainable. The Commission suggests that root and branch reform of aged care is necessary

In summary the principal elements of the reforms they have proposed are:

- 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.

- Increased access to community care including, by removing the link between care and accommodation and expanding community care packages.
- Improved access to information and assessment through a networked gateway designed to bring together information and assessment to enable consumers to know where they should go more easily to gain information on services and to be assessed for services.
- A commitment to consumer directed models of care to better meet consumer needs through flexible services
- Changes to the user pay system to create a more sustainable aged care system.
- A recognition of the importance of addressing work force issues
- Lastly, improved access to end of life care, advance care planning and palliative care.

It is disappointing to consumers that there is no recommendation in the report that addresses dementia even though dementia is the core business of aged care. In Australia the majority of residents in aged care have dementia, it is one of the most disabling of all conditions among older people and is one of the major causes of institutionalisation.

At the same time, the quality of dementia care can not be addressed purely through reform of the aged care system. There needs to be a comprehensive approach to address the needs of people with dementia across both the health and aged care system. There is a need for a new paradigm in the development of dementia policy.

A new paradigm?

Dementia is one of the major chronic diseases of the 21st century. There are nearly 280,000 people with dementia now and this is expected to rise to nearly a million by 2050. Dementia will become the third greatest source of health and residential aged care spending within two decades. By 2060 spending on dementia is set to outstrip any other health condition.

Yet dementia is still not acknowledged as a national health priority. Dementia should be acknowledged as a major chronic disease by those responsible for health policy. Dementia needs to be addressed, like other chronic conditions, through risk reduction, timely diagnosis, good management, and quality care. If the public health framework developed for other chronic diseases is good enough for cancer, heart and diabetes it should be good enough for dementia.

There seems to be an assumption in the work of the Productivity Commission that simply by reforming aged care, services will be improved for everyone, including those with dementia.

History suggests otherwise. There is a need to recognise the special requirements and costs incurred in the provision of dementia care. A few examples may help to illustrate the point.

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

There has been scant recognition of the importance of respite care that is flexible enough to meet the needs of the family carers, and also provides support and activities for the person with dementia.

Again it has been problematic to get recognition of the extra funding needed to care for those with severe behavioural and psychological symptoms of dementia, because of divided responsibilities between the mental health systems and aged care.

Over the last decade Alzheimer's Australia has sought to ensure funding and incentives that respond to the special needs of those with dementia including through the development of the Aged Care Funding Instrument, Extended Aged Care at Home Dementia packages and the other elements that were included in the 2005 Dementia Initiative namely training, dementia care research, Dementia Behavioural Management Advisory Services and support services through Alzheimer's Australia.

And there are no age appropriate services for young people with dementia.

The key issue is the need to look beyond the age care system if there is to be prospect of tackling the dementia epidemic in a comprehensive way. The major failure of the last decade has been the failure to respond to pleas from people with dementia and their families for a plan to address 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 reduce the risk of dementia
- Investment in research to better understand the causes of dementia and the ways to slow progression and prevent dementia

Fight Dementia Campaign

Australia needs a comprehensive funded plan to address dementia across the health and aged care system. In the last federal budget, the Government announced the

termination of the Dementia Initiative which provided a focus for dementia policy. This has left Australia with out a focus or a plan to improve services for the increasing number of people with dementia.

Alzheimer's Australia has proposed the 'Fight Dementia Action Plan' as a way forward and has undertaken a Campaign to promote this plan.

The Campaign has three major objectives:

1. To address dementia in the broader context of health and aged care policy
2. To redress the failure of the Productivity Commission report to address concerns about the quality of dementia care
3. To secure a Dementia Action Plan to combat dementia given the unfortunate decision in the 2011 Budget to terminate the dementia initiative

The Fight Dementia Campaign is seeking $500 million over 5 years to the address carefully targeted priorities set by people living with dementia. The framework as I have said is consistent with the public health framework adopted in respect of other chronic diseases.

We well understand that this is a time of economic restraint and the reasons for that. But it is almost modest to seek $100 million a year to address neglected priorities in respect of 280,000 people with dementia today and over 400,000 within 10 years.

$100 million per annum represents about 2 per cent of the direct care costs of dementia. Australia cannot afford to continue to ignore the needs of people with dementia.

Now, let me take the elements of the proposed Dementia Action Plan in turn briefly.

- **Information and Awareness**

Market research suggests that Australians have a limited understanding of the symptoms of dementia beyond memory loss, that it can affect younger people, that it is a terminal disease, that symptoms develop decades before diagnosis, that medications are available to relieve symptoms in the short term or that lifestyle changes may offer some potential for in risk reduction.

For people who have dementia, this lack of community awareness and understanding can lead to stigma and social isolation.

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 in the way we have with other chronic diseases.

- **Timely Diagnosis**

The major report released by Alzheimer's Disease International and prepared by the Institute of Psychiatry College in London that was released in September last found that in high income countries only 20%-50% of people living with dementia are recognised in primary care.

A publication released by Alzheimer's Australia last September ***Timely Diagnosis of Dementia; can we do better?*** found that on average people with dementia wait 3.1 years from first noticing symptoms of dementia to receiving a firm diagnosis. These are years lost to the person with dementia and their family carer in planning for the future.

It is not only the absence of a simple test and the complexity of dementia that creates delays in diagnosis. There may be reluctance on the part of the individual or their family carer to seek help because they fear of loss of independence or have concerns about how dementia is perceived and the stigma that attaches to it.

General Practitioners for their part may have difficulty differentiating normal ageing from dementia and may not be aware of the benefits of early diagnosis. There may be an attitude that since there is no therapy there is no point in making a diagnosis.

Doctors may also fear damaging the doctor–patient relationship; lack skills in communicating the diagnosis or have a desire to protect the patient from the diagnosis.

Some GPs may be reluctant to diagnose if they think there are no services or specialists in their area that can assist the individual. Time-limited consultations may also be a factor.

Complex though these factors are there are strategies that may address them including

• Patient/carer strategies to increase awareness of dementia, including checklists for those concerned about their memory, and what the 'normal' ageing process is.

• Strategies to better support GPs at the service level by training and education through workshops, incentives to spend more time in the assessment process, incentives to spend time with carers to better understand the issues in relation to their patient.

• System change to make more effective use of practice nurses to assist with the screening process and a greater emphasis on a team approach perhaps through the new Medicare Locals

The Australian General Practitioners network has invited Alzheimer's Australia to partner with them in making a funding application to the Federal government to implement training strategies through Medicare Locals.

- **Support and Care**

In addition to the recommendations made in the Productivity Commission's report Alzheimer's Australia is advocating for reforms that include:

- A funding model that recognises the extra costs of dementia care
- Expanding 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 individuals with younger onset dementia that are age appropriate
- Co-ordination of the aged care and mental care systems to address the needs of individuals with behavioural and psychological symptoms of dementia

I should then add that Alzheimer's Australia is particularly supportive of the recommendations made by the Productivity Commission for trialling the cashing out of respite care. Available evidence suggests that for every three carers who have used respite, there are two dementia carers who need respite but have not used it. 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 than other carers to need and have used respite; and
- More than 10 times more likely than other carers to say they need respite but had not used it

We believe that a trial with independent evaluation would help set the scene for the implementation of greater flexibility in a key area of service delivery for people with dementia and their families.

- **Acute care**

The evidence in Australia and internationally is that people with dementia receive poor quality care in hospitals and that poor quality care leads to worse outcomes and longer stays. The issues are clearly of importance given the growing of numbers of people with dementia.

In 2009 and 2010 54% of people in hospitals were over the age of 55. It seems probable that this number will only grow with the ageing population and that there will be a larger number of people in hospital with some form of cognitive impairment. A recent report indicated that amongst older people in hospitals, the rate of cognitive impairment was about 45%.

The costs associated with poor quality care will only become a greater problem, with a projection of hospitalisations of individuals with dementia set to quadruple over the next few years due to population ageing.

Consumer concerns centre on lack of understanding of dementia by hospital staff, the need for assistance with eating, drinking, person centred care, and opportunities for social interaction.

The policy conclusion seems to be that patients with dementia in hospital maybe be more appropriately treated in alternative settings and length of stays maybe reduced by more appropriate services in the community.

This is an area in which we would like to see joint Commonwealth-State action.

- **Risk Reduction**

There is some difference of view about dementia risk reduction. The National Institute of Health in the USA expressed some uncertainly about the interpretation of population studies in the association of dementia and a number of risk factors and the need for more long term studies. They asked “are people able to stay mentally sharp because they are physically active and socially engaged or are they simply able to stay physically active and socially engaged because they are mentally sharp?”

Alzheimer’s Australia takes a different view. We consider there is now evidence to support the view that lifestyle changes may reduce the risk of dementia in some people. For example, there is now clear evidence that vascular dementia has the same risks factors as heart disease.

Even without a clear causal link there is no harm in advocating for healthy lifestyles that may have a positive impact on brain health.

Market research indicates that 50% of Australians are unaware that they may be able to reduce their risk of dementia. And among those who are aware there is a low understanding of the potential benefits of reducing high blood pressure, cholesterol and head injuries.

Alzheimer’s Australia is seeking funding to role out the public education program “Mind you Mind” to promote a wider understanding of dementia risk reduction.

We also believe the Government should make a connection in their preventive health programs between physical health and brain health - for example, in the context heart and alcohol consumption.

- **Research**

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, the National Health and Medical Research Council research funding for chronic diseases was $144 million for cancer, $97.4 million for research on cardiovascular diseases, $63.1 million for diabetes. Alzheimer’s diseases and other types of dementia received only $19.3 million.

In Australia we spend over $5 billion a year on the direct health costs of dementia and projections suggest that dementia will become the third greatest source of health and residential spending in two decades and the largest by 2060.

Meanwhile we invest less than 0.5 per cent of the cost of dementia each year. The Fight for Dementia Campaign proposes we spend 1.0 per cent – surely not overly ambitious.

Where now?

I suggest we now know what needs to be done and that there is a reasonable evidence to support it. Our conclusion has been to adopt a Fight Dementia Campaign and to communicate in a much more vigorous way the stories of people with dementia and their family carers.

On 13th October five hundred carers and people with dementia from across Australia marched on Parliament House. We have implemented a new marketing and branding strategy with the Fight Dementia campaign that has already made an impact.

We want aged care reform but we also want action to improve the quality of dementia care. And to quote the Minister “Aged care reform that does not have a dementia response at its heart will not be successful”

From a consumer viewpoint achieving the objective of enabling older people and people with dementia to stay longer in their homes will remain a cruel dream unless there is an immediate and significant expansion in community care, the implementation of more flexible respite including a trial of cashing out and the adoption of consumer directed models of care beyond the current respite and community packages.

I hope you are persuaded that aged care reform is not in its self enough in respect of dementia. There is a need for specific attention to dementia in aged care reform together with action on timely diagnosis, acute care, risk reduction and investment in dementia research.

None of this is rocket science. The principles of a good public health framework have been well established. People with dementia and their families should not be second classed citizen in our health system.

The Fight Dementia Campaign is about beating dementia – finding better solutions to care for people and through research eventually reducing the numbers of people with dementia. We now know enough about dementia and its pathology to have some optimism about identifying those at most risk and developing strategies that may delay the progression of this insidious illness.

Once we thought about senile dementia in terms of a natural part of ageing. Let's adopt a new paradigm in the 21th century which acknowledges dementia as a major chronic disease.

I invite everyone to sign up as a Dementia Champion on the campaign website: www.campaign.fightdementia.org.au