

## **DEMENTIA CONGRESS MELBOURNE – FEBRUARY 2011**

Many thanks to the organisers for inviting me to speak again at this second Dementia Congress.

When I accepted the invitation, we did not have the draft report of the Productivity Commission on Caring for Older Australians. The Commission had indicated that they would be seeking to reform the aged care system in a way that would better respond to the needs of older Australians.

The Productivity Commission have kept to their word, and set out in their Draft Report a new vision for aged care, one of greater choice, flexibility in service delivery and personal responsibility.

Alzheimer's Australia has long advocated for many of the proposed reforms. These include separating accommodation and care, increasing priority for community care, improving access to coordinated assessment and information and greater flexibility in service delivery.

In that sense, the Productivity Commission have responded to consumer demands for reform. There is of course, a way to go before we have the final report of the Commission at end June, and the Government's response to the recommendations later in the year.

The National Aged Care Alliance which comprises 28 consumer, provider, unions and professional organisations has welcomed the transformational reform that the report represents.

The unease about the report, for most of us in the sector, is more about the issues that require further discussion or are not addressed than the philosophy and principles that underpin the report.

There is unease for example about

- How the market will work and how possible market failure will be addressed for example in respect of the homeless or in rural areas.
- The absence of a mechanism for the delivery of fair and competitive wages.
- The approach to consumer co-contributions and asset testing and the implications for the social welfare system.
- How the needs based assessment approach will work and how governments will manage it to control costs.
- How the reform can create a system that focuses on quality rather than minimum standards.
- The complexity of designing a funding model applicable across community and residential care.

And it is encouraging that Minister Butler has committed to consulting with the sector at the National level through the National Aged Care Alliance. The Alliance is ready to collaborate with the Government to work through these and other more detailed issues to achieve reform.

And consumers will have a voice through consultations being organised by National Seniors, COTA and Alzheimer's Australia.

Alzheimer's Australia takes the view that people living with dementia – both those with a diagnosis and family carers– will benefit from the proposed approach to the reform of aged care.

Unfortunately there appears to be little understanding or recognition in the Draft Report that dementia is and must be the core business of aged care services. Around 60% of residents in aged care have dementia- and this is likely to increase with the increasing prevalence of dementia.

It is a disappointment that the Commission regards dementia in aged care in the same way as it might regard diabetes; as just another chronic condition.

This is not the case.

Dementia is one of the most sobering conditions we face as human beings. It involves the progressive loss of memory, language and functioning and in the later stages, requires specialist care. Dementia is one of the most disabling of chronic health conditions, and we do not yet have a cure.

Dementia complicates the management of all other conditions because the individual may not be able to self medicate or communicate their needs.

We also know that despite good evidence on what should be done, there are many areas of dementia care that are sadly lacking in quality. Pain management is often poor, and there are many cases of people who cannot verbally articulate their needs being left in severe pain – sometimes with fractures or pressure sores – for days. There are also cases where people's prior wishes regarding end-of-life care are not respected, and invasive clinical interventions lead to individuals spending their final days in the confusion and isolation of a hospital, rather than receiving quality palliative care surrounded by family and familiar environs at home.

As well as the personal impact, the economic consequences of dementia, as one of the most disabling of chronic conditions are daunting. Let me read you some figures:

- The cost of dementia care in 2008 is estimated at \$5.4 billion per annum. <sup>i</sup>
- Dementia will become the third greatest source of health and residential aged care spending within two decades. These costs alone will be around 1% of GDP. <sup>ii</sup>
- By the 2060s, spending on dementia is set to outstrip that of any other health condition. It is projected to be \$83 billion (in 2006-07 dollars), and will represent around 11% of the entire health and residential aged care sector spending. <sup>iii</sup>

- The opportunity cost of dementia through lost productivity born by individuals, business and government was estimated at \$881 million in 2008.<sup>iv</sup>

The economic impact of the increase in the number of Australians who will have dementia can be seen in the workforce implications. It has been estimated that there will need to be an increase of over 150,000 carers for people with dementia in 2029 relative to 2008 – a 76% increase in the 2008 workforce. This shortage is made up of 58,000 paid dementia care staff and 94,000 family carers.<sup>v</sup>

The social dimensions of dementia are equally dramatic. Caring for a person with dementia is particularly challenging, with the progressive degeneration of the person's cognitive capacity and ability to undertake the activities of daily living.

As a consequence, carers often experience negative social and health effects of their caring roles. Social impacts may include loss of work and social activities. Health impacts can include depression, anxiety, stress, physical conditions and sleep disruption.

The social cost of dementia on Australian families is enormous.

- Dementia impacts on the lives of over a million Australians who provide support for people with dementia in one way or another – from helping with shopping to 24-hour care.<sup>vi</sup>
- In many cases, family carers may be the only source of care for people with dementia. In 2008, 37% of people with dementia received no formal care in the community.<sup>vii</sup>
- The cost of replacing family carers with paid carers in 2008 is estimated at \$5.5 billion per annum.<sup>viii</sup>

In short, dementia should be a central consideration in the reform of aged care. Alzheimer's Australia would like to see the Productivity Commission address a number of issues in more depth and to carry this into their recommendations.

On a first analysis of the Draft Report the issues of most concern to us in the context of dementia are:

- 1) A need to build on the work of the Dementia Initiative – Making Dementia a National Health Priority.
- 2) The interface between aged care and mental health.
- 3) A specific funding model that recognises the additional costs of dementia.
- 4) Networking the proposed seniors gateway to the information and counselling systems already in place through NGOs such as Alzheimer's Australia.
- 5) Respite care and dementia
- 6) Care for individuals from Special Groups

### **1) The Dementia Initiative – Making Dementia a National Health Priority.**

The Draft Report makes no reference to the Dementia Initiative and the role it has played in promoting awareness of dementia, improving the quality of care, increasing access to community care or enhancing dementia care research.

From a consumer perspective, the Dementia Initiative has been effective, and an independent evaluation commissioned by the Commonwealth Government has reached a similar view in recommending it should be continued, and in some areas, strengthened and gaps addressed.

Specifically, the Dementia Initiative has resulted in:

- Improved access to specialist dementia services in community care through access to the Extended Aged Care at Home (Dementia) packages in the community.
- Increased community engagement in dementia through community grants and sector development grants and the awareness and community education activities made possible through funding for the National Dementia Support Program (NDSP) administered by Alzheimer's Australia.
- Funding increases in dementia care research through the three Dementia Collaborative Research Centres and dementia research grants.
- Improvement in the quality of dementia care through the Dementia Behaviour Management Advisory Services.
- Greater opportunities for workforce education and training through Dementia Care Essentials and the Dementia Training Study Centres.
- Better access to support for people with dementia and their family carers through targeted resources and improved funding through NDSP.

The Initiative is of strategic importance in ensuring that through well targeted funding, improvements are made in the quality of dementia care. The Dementia Initiative should be built upon to further improve the quality of dementia care by taking initiatives designed to:

- Promote timely diagnosis of dementia. The journey with dementia is difficult enough without delays in the diagnosis of dementia, having it communicated in an insensitive way or not being referred to support services that may be of help to the person with dementia and their families.
- Improve hospital care. Hospitals are dangerous places for people with dementia. In part, this is because of a lack of processes to make staff aware that a person may have dementia. This can result in falls, medication errors, or poor nutrition. The UK National Audit Office has estimated that in the UK, each hospital could save an average of £6 million a year by correctly identifying dementia patients, providing more appropriate and timely care, thus reducing the length of stay and improving health outcomes.
- Adjusting funding for counselling and support services in line with the growth in numbers of people with dementia.
- Promoting greater awareness and understanding of dementia and in particular, of the potential for reducing the risk of dementia by changed lifestyles.

## **2) The interface between aged care and mental health.**

Individuals with severe behavioural needs often face problems with continuity of care because of barriers between the state-funded mental health system and the Commonwealth funded aged care systems.

The aged care system is best positioned to care for this group and hence the Commonwealth Government should take responsibility. To quote the Expert Psycho-geriatric Group in the Draft Report “there will be much higher numbers of older people with mental illnesses in years to come that will require management in generic settings”.<sup>1</sup>

A Report to the Minister for Ageing on Residential Care and People with Psychogeriatric Disorders made several recommendations on how to improve the care provision for people with Behavioural and Psychological Symptoms of Dementia<sup>2</sup>. The report suggests that an ‘optimal’ system of care for this group would include high dependency units for time limited care. These units would be designed to meet the mental health and aged care needs of this group

Individuals with psycho-geriatric disorders require a higher level of care provided by highly trained staff and as a result their care is much more costly. The Aged Care Funding Instrument provides a behavioural supplement but this supplement does not cover the true costs of providing care for those with severe behavioural concerns. The Commission acknowledges these concerns and suggests that they will be addressed by the new benchmarking of the cost of care services.

The new funding system must include a supplement which covers not only the additional costs of care for individuals with moderate behavioural concerns, but also those with severe behaviours including aggression.

## **3) A specific funding model that recognises the additional costs of dementia.**

The Commission discusses a number of possible funding models, but makes no specific recommendations.

The Productivity Commission contracted Applied Aged Care Solutions to provide an independent report on a new care and assessment model they have recommended a layered funding model which would provide basic support and care with supplements based on care needs including a two level dementia/mental health subsidy. The model would provide a single funding stream with three components:

- A base subsidy which would be determined based on low to high IADL/ADL needs at 4 levels.

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<sup>1</sup> Psychogeriatric Care Expert Reference Group Submission to the Productivity Commission (2010).

<sup>2</sup> Report to the Minister for Ageing on Residential Care and People with Psychogeriatric Disorders (2008).

- Layered supplements covering specialist areas including dementia, mental health, palliative care and nursing, with two levels of funding for each supplement.
- Care support needs. For example, home modifications, transport, rural and remote care.

Individuals with dementia who have psychological and behavioural symptoms often find it difficult to access aged care. In many cases this is due to providers not receiving adequate funding to provide the high-level specialised care required. As the Hogan report noted “A resident who is mobile, wanders, has dementia and challenging behaviours - not once but many times a day - may well require constant supervision, continuous staff intervention, redirection and intervention to prevent risks of falls, episodes of aggression and increased anxiety levels. The resident is also likely to resist care and hence require considerable time and effort from staff to meet care needs.”<sup>3</sup>

The layered funding model proposed by the AACS includes a dementia subsidy across three levels of care regardless of where the care is provided. This is a step forward compared to the current model in which dementia/behavioural supplements for community care are only available for individuals requiring high-care through EACH-D packages.

The Productivity Commission should commit to a layered funding model that includes a dementia supplement across all layers of care but additional consideration must be given to how to accurately assess the additional costs of care associated with dementia. The proposed two level subsidy for dementia and mental health may be too simplistic.

The details of this supplement should be developed in consultation with consumers, providers and experts such as the Psychogeriatric Care Expert Reference Group.

#### **4. The Gateway**

The Productivity Commission has responded to consumers concerns about streamlining access to information and assessment. The Commission proposes a Gateway that would be the access point for all government subsidised aged care and support services and would include:

- Information on healthy ageing, age appropriate housing, and social inclusion.
- Information on availability, quality and cost of care services and how to access these services.
- Assessments of the needs of older people to determine entitlement to care
- Assessment of financial capacity to make co-contributions
- Initial care coordination services.

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<sup>3</sup> Hogan (2004). Review of Pricing Arrangements in Residential Aged Care.

The gateway would deliver services via a regional structure. The Commission indicates that many programs that are currently receiving block funding from the Government would receive funding through the entitlement system and would therefore be accessed through the gateway. Exceptions would be made where “scale of economies, generic service need and community involvement indicates there is a need to do so”.

It is unclear how the gateway would interact with NGO's like Alzheimer's Australia that provide information, counselling and support services.

Under the National Dementia Support Program (NDSP) Alzheimer's Australia is able to provide an integrated suite of services to people with dementia and their families.

Every year this program enables Alzheimer's Australia to provide over 120,000 Australians with world class information, resources, skilled dementia counselling, support groups, education and training for both carers and care workers. In addition, the program provides early intervention strategies such as the Living with Memory Loss programs, and centre-based and outreach support programs. These programs have been found to be effective in reducing stress for both the person with dementia and their carer by providing structured information and support.

The objective of these services is to encourage those with concerns about their memories to get help sooner rather than later. For obvious reasons many will be in denial about their problems.

People may be less likely to access services if, under the new gateway, they are required pay a co-contribution. As a result some individuals may choose to not access services until they hit a crisis point, which will result in worse outcomes for people with dementia as well as the public health system. Those who are willing to pay may face a delay in accessing services while they wait for an assessment.

If organisations like Alzheimer's Australia continue to receive block funding, the Gateway could provide referrals to these organisations to encourage care recipients and carers to access specialised counselling and support.

## **5. Respite care.**

Respite care is discussed by the Productivity Commission, but in the view of Alzheimer's Australia, this discussion is insufficient and does not acknowledge the importance of respite to both the carer and the care recipient or the need for reform.

Respite care enables many individuals with dementia to continue to live at home for as long as possible.

Unfortunately, many family carers of individuals with dementia have difficulty accessing respite services that meet their needs. According to the most recent Survey of Disability, Ageing and Carers in 2003, for every three carers who have used respite, there were two who indicated a need for respite but had not used it.

The differences between need for and use of respite on the part of dementia carers are striking. Dementia carers are more than 10 times more likely than other carers to say they need respite but had not used it.

In 2009 Alzheimer's Australia released a publication, *Dementia and Respite Care: "More than just a short break"* which recommends major changes in the provision of respite care. Based on that analysis the Commission should make recommendations that reflect:

- The need for respite that responds to the needs of people with dementia as well as those of family carers.
- A new funding model for respite that does not make divisions between where respite is provided
- The importance of consumer directed care in the context of respite services, including through the option of cash entitlements..

## **6. Special groups.**

The Productivity Commission makes some important recommendations to overcome concerns about the under-representation of those from CALD and Indigenous communities in aged care services. These include:

- Improving access to information for these groups through the proposed Gateway.
- Provision for extra funding provision to cover special needs through the assessment process.
- The use of culturally appropriate tools such as the Kimberley Indigenous Cognitive Assessment, and
- Increasing adequate infrastructure and staffing resources in remote and Indigenous communities.

In the context of dementia, these recommendations do not go far enough.

The needs of people from CALD and Indigenous communities can be especially difficult in the context of dementia. There may be lower levels of awareness and negative cultural attitudes to dementia which combine to foster later entry into support systems. This combines with the challenge of finding services which are culturally appropriate and can provide dementia care.

We recognise the strength of what the Commission is proposing, but suggest they go further in two ways.

First, to recognise the importance of a partnership approach in promoting dementia awareness among CALD and Indigenous communities.



Secondly, to consider whether a cash entitlement for community care and respite care would enable individuals from these groups to access culturally and linguistically appropriate care and support within their own community.

## Conclusion

The transformational reforms proposed by the Productivity Commission are an exciting step forward to a new world of choice and flexibility for consumers but there is still much to be done.

Over the next few months there will be extensive consultation with the aged care sector, including the National Aged Care Alliance to fill in the details of the final report and to ensure that important issues, like psycho-geriatric care and workforce, receive more attention.

After the final report we will wait with great anticipation to see the Government's response.

Much work must still be done around the transition arrangements. Alzheimer's Australia understands the Commission's rationale for pushing ahead with reform quickly and the risk of losing the impetus. There is a need to take service providers, consumers, staff and professionals along with each stage of the reform processes.

These reforms will not only require changes in legislation and regulation but also a major cultural shift for aged care providers, workforce and consumers. A longer transition period would ensure true change in the philosophy of aged care provision in Australia and the adequate functioning of the proposed safety nets. Opportunities for true reform are infrequent, and the greatest risk to this reform process is inadequate transition and implementation arrangements.

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<sup>i</sup> Access Economics (2009) *Making Choices: Future Dementia Care: projections, problems and preferences*, A report for Alzheimer's Australia, April.

<sup>ii</sup> Access Economics (2009), *Front of Mind*, Report for Alzheimer's Australia. August.

<sup>iii</sup> Access Economics (2009), *Front of Mind*, Report for Alzheimer's Australia. August.

<sup>iv</sup> Access Economics (2009) *Making Choices: Future Dementia Care: projections, problems and preferences*, A report for Alzheimer's Australia, April.

<sup>v</sup> Access Economics (2009) *Making Choices: Future Dementia Care: projections, problems and preferences*, A report for Alzheimer's Australia, April.

<sup>vi</sup> Based on independent market research for Alzheimer's Australia and published in Pfizer Australia Health Report, Issue 6, 2004.

<sup>vii</sup> Access Economics (2009) *Making Choices: Future Dementia Care: projections, problems and preferences*, A report for Alzheimer's Australia, April.

<sup>viii</sup> Access Economics (2009) *Making Choices: Future Dementia Care: projections, problems and preferences*, A report for Alzheimer's Australia, April.