

Australia's Ageing Populations Summit, 25 – 26 June 2009
Dementia: The Priorities –responding to the needs of Australians of all ages-

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Many thanks to Informa for including the issue of dementia on the agenda of Australia's Ageing Populations Summit.

While I will be focussing on dementia I should make the point at the outset that the quality of life for people with dementia will depend not only on decisions to be taken by the Federal Government in the 2010 Federal Budget on the Dementia Initiative - Making Dementia a National Health Priority but also on the decisions taken on the Final report of the National Health and Hospitals Commission and particularly the recommendations on aged care.

The Interim report of the NHHRC on Greater Choice in Aged Care holds out some promise of much needed reform in aged care services. And it is promising that the approaches set out in the Interim report have been generally welcomed in the aged care sector.

Dementia is the term used to describe the symptoms of a large group of conditions (over 100, in fact) which result in progressive decline in cognition, including decline in memory, reasoning, communication skills and the capacity to carry out activities of daily living. At some stage of the illness, individuals are likely to develop behavioural and psychological symptoms including depression, psychosis, aggression and wandering.

Research over the last twenty years has provided a good understanding of the changes in the brain that lead to the death of brain tissue, but as yet the causes of dementia are not well understood.

The main types of dementia are Alzheimer's disease and vascular dementia, or a mixture of the two pathologies. Increased risk of dementia is associated with vascular disease, Parkinson's disease, Huntington's disease, obesity, diabetes, alcohol and drug misuse and intellectual disability.

I would like to remind you why dementia is both one of the most common as well as the most disabling of all chronic conditions.

In summary:

- There are over 230,000 Australians with dementia with more than 1,000 new cases every week.
- By 2030 there will be 460,000 people with dementia and by 2050 over 700,000.
- The current direct healthcare cost of dementia is estimated at \$5.4 billion.
- The opportunity cost or lost productivity born by individuals, business and Government is estimated at \$881 million in 2008. If carer costs are based on replacement cost, then the figure would be \$ 5.5 billion.
- Dementia is the fourth largest cause of death for those over 65 years of age.

- By 2023 dementia is the chronic disease projected to show the greatest increase in disease burden for those over 65 years.

The economic impact of such a rapid increase in the number of Australians who will have dementia and need services in the future will be reflected in the workforce implications. In the most recent report Alzheimer's Australia commissioned from Access Economics, ***Making Choices: Future Dementia Care***, it is estimated that there will need to be an increase of over 150,000 carers for people with dementia in 2029 relative to 2008. That's a 76% increase in the 2008 workforce.

This shortage is made up of 58,000 paid dementia care staff and 94,000 family carers.

When we're discussing how to respond to the needs of people with dementia of all ages it is important to understand that dementia is a social condition as well as a medical one. It attracts stigma, social isolation and discrimination. These factors compound the difficulty of the dementia journey that may take place over many years.

Nor is dementia a condition of concern only to older people. While the most important risk factor is age, research evidence suggests that the pathology of dementia develops decades before diagnosis.

Moreover, there are 10,000 Australians under 65 with dementia. The social and economic impact on these individuals and their families is particularly difficult as they may have children, experience loss of employment and difficulty accessing services that are appropriate for younger people.

I will talk about:

- 1) The Dementia Initiative - Making Dementia a National Health Priority.
- 2) The diagnosis and treatment of dementia.
- 3) The care and support needs of people living with dementia.
- 4) Staff interaction with people with dementia – staff training.

The Dementia Initiative

The decision in the 2005 Budget to make dementia a National Health Priority was a landmark decision, not just in Australia, but worldwide. Additional funding of \$320 million over five years was included in the 2005 budget.

Australia can be proud of being the first to acknowledge the economic and social impact of dementia. Other countries are following, and at the international level Alzheimer's Disease International and Alzheimer's Europe are advocating for dementia to be made a health priority with the World Health Organisation and national governments.

The three measures included under the Dementia Initiative are:

- 1) Dementia – A National Health Priority: Initiatives to support dementia research innovation, dementia and approved care and dementia prevention and early intervention (\$70.5 million over five years).
- 2) The introduction of 2000 Extended Aged Care at Home (Dementia) packages (\$225 million over five years).
- 3) Training to care for people with dementia (\$25 million over five years).

The evaluation of the Dementia Initiative commissioned by the Federal Government is not yet available. Until we see that report we cannot be certain about how cost effective the Dementia Initiative has been in producing positive outcomes for people with dementia and their family carers. On the basis of their Interim Report we expect the final report to identify gaps and areas where improvements can be made - for example, they might advise a significant increase in the funding of a national communication campaign to promote awareness and understanding of dementia.

The Dementia Initiative has achieved much of its promise. Most obviously it has resulted in a wide range of new initiatives including three new Dementia Collaborative Research Centres, dementia research grants, expansion of the National Dementia Support Program, Community Grants, Sector Development Grants, Dementia Behaviour Management Advisory Services, expanded training activity, Dementia Training Study Centres and care packages.

From a consumer perspective the Dementia Initiative has

- Provided an opportunity to demonstrate the potential of greater choice to consumers through access to Extended Aged Care at Home (Dementia) packages in the community.
- Fostered community engagement through community grants, program grants and the awareness activities and consumer support made possible through the National Dementia Support Program administered by Alzheimer's Australia.
- Injected some much needed additional funding into dementia care research, attracting younger researchers into the area and positioning dementia researchers better to apply for NH&MRC and other grants.
- Contributed to improving the quality of dementia care through increased dementia training.
- Resulted in greater consumer involvement through the Minister's Dementia Advisory Group.

The Government is to take decisions on the future of the Dementia Initiative in the 2010 budget. Both major political parties are committed to continuing the existing funding. While we would expect, therefore, many of the existing initiatives to continue, the challenge will be to get additional resources to respond to new priorities.

Essentially, we take the view that the major challenge is to achieve a public health policy that reflects dementia as a real health priority and not just as an issue for aged care. Action is needed in primary care, acute care and prevention.

So let me turn to three of the areas that are priorities in terms of our thinking about how best to respond to the needs of people with dementia of all ages and cultures regardless of where they live.

The Diagnosis and Treatment of Dementia

First, the diagnosis and treatment of dementia.

There are significant and longstanding concerns among people with dementia and their carers about the failure of the primary care system to support effective diagnosis and ongoing care of people with dementia. Improved access to primary care for people with dementia will not eventuate unless there is a specific focus on people with dementia.

Early intervention though improvement in diagnosis is important because it:

- Provides the opportunity for people with dementia and their families to better plan, including their finances and future care arrangements.
- Removes the uncertainty and trauma that comes with the delays experienced in the diagnosis of dementia by many, and particularly those with younger onset dementia.
- Is multifaceted and fits with the complex and chronic care model. Most people with dementia are older and have co morbidities such as hypertension, diabetes, depression and arthritis, all of which may be complicated by the presence of dementia.

Most recently, in Alzheimer's Australia's response to the National Health and Hospital Reform Commission's Interim Report, we argued that dementia is a chronic condition that would benefit from coordinated care planning. This is because dementia often presents with other chronic co-morbidities and also affects ability to self manage health conditions. Any coordinated care model for enrolled patients must include care planning and pathways for patients with dementia.

Specifically, we believe that there is a need for action to:

- Provide Medicare incentives to promote timely and accurate diagnosis and support for people with dementia and family carers in ongoing management.
- Link these incentives to opportunities for dementia training for all GPs, practice nurses, nurse practitioners and other primary health professionals as appropriate.
- Foster a multidisciplinary approach supported by access to a network of specialist services to people with dementia regardless of their age and location.

I'd like to see Australia follow the lead of the UK National Healthcare Service in developing a five year strategy to train all GPs in dementia and give them better support in diagnosis. Any new approach, if it is to work, must provide for GPs to have good specialist support as well as practice nurses to assist in the assessment and care of people with dementia.

The Care and Support Needs of People with Dementia.

About 70 per cent of the care in the community needed for people with dementia is provided by family carers. The need of family carers for support and services will vary greatly. 37 per cent of people with dementia in the community receive no formal care. The needs of those living with dementia are dependant on their individual circumstances, including their health, finances and understanding of dementia.

The choice modelling survey undertaken by Access Economics in the report ***Making Choices: Future Dementia Care*** differs from other types of surveys in that respondents were not asked directly what attributes they valued. Instead, the value placed on each attribute is implicitly revealed by observing the choices that respondents made between different scenarios.

For community care the outcome of the choice survey was that:

- Home support services (such as shopping, transport and cleaning) were valued by family carers highest; the increase in demand for a care option with home support twice a week compared to one with no home support was around 55%.
- Respite services available daily and for extended periods of time were also valued highly; a care option including this attribute would have 48% higher demand than one that did not include regular respite.

Home support and respite occupied the top five spaces in terms of ranking community care attributes.

In residential care, the outcome of the choice survey was that:

- A private room and bathroom were most highly valued with over 50% higher demand than an option without these facilities.
- Skilled residential aged care workers specialising in providing dementia care were next most highly valued with 46% higher demand compared to minimum legal standards of care.

Alzheimer's Australia believes the priorities for improving access to quality dementia care for Australians of all ages and cultures regardless of where they live include:

- An expansion of packages designed for people with dementia on the model of the Extended Aged Care at Home (Dementia) packages.
- An expansion of respite care services that respond flexibly to the needs of both people with dementia and their family carers. There should be more long day respite care for carers in the workforce.
- Ensuring that respite services are not just used as a means of providing the carer with a short break. Such services also need to respond to the social and cultural needs of people with dementia of all ages by engaging them in appropriate activities.
- The planning and allocation of dementia specific residential places for those with special needs, including, for example, those with both dementia and psychiatric needs and those with younger onset dementia.
- The development of quality dementia care standards by the Standards Accreditation Agency.

- The allocation of places for dementia specific care. There is no reliable data at present on the number of such places.
- Measures to make the acute care sector a less dangerous place for people with dementia.
- A recognition in the Government funding of Alzheimer's Australia that partnerships with CALD and Indigenous organisations need to be properly resourced if we are to achieve the objective of greater awareness of and access to services for those groups as part of mainstream program activity.

Staff Interaction with People with Dementia.

Like all of us, every person with dementia has his or her own unique, individual personality. There is no single or standard approach to dementia care – no “one size fits all” set of practices – that is most appropriate for people with dementia. Alzheimer's Australia has taken the view that the quality of dementia care is likely to be high if it is driven by a person-centred care approach: that is, a partnership between service providers, the person with dementia and the family carer, delivered in a service environment characterised by strong leadership and the adoption of best care practices.

The differing individual needs of the person with dementia and their family carers necessitate flexible and responsive approaches to care services. Alzheimer's Australia advocates adopting the Consumer Directed Care model in care packages and respite care so that it is consumers, if they wish, who determine the services needed and how, when and where they will be provided.

The person-centred care approach encourages a focus on the interaction between staff and the individual through for example acknowledging the importance of the individual's personal story. Consumer Directed Care takes that thought further and empowers the consumer themselves to express their service needs. If consumers do not know what funds are available to them, and have little say about what services are to be provided it seems probable that good interaction between staff and consumers will be that much harder to achieve.

In the first instance, Alzheimer's Australia has advocated for models of Consumer Directed Care to be embodied in Commonwealth community care packages and the National Respite for Carers Program. The gradual adoption of Consumer Directed Care and its evaluation over time will be important in the potential for better staff interaction with people with dementia and their family carers.

In the longer term – and it is a much more distant dream – consumers should have the choice of that mix of care and accommodation option that best suits their particular needs. This may be, for example, periods of residential care rather than the commitment to long term residential care. The split of care from accommodation holds out new and interesting possibilities in the future.

Training has formed an important part of the Dementia Initiative and has an important part to play in promoting positive staff relationships through person centred care. There has been an expansion of training at the Certificate three level and at the

tertiary level through the Dementia Training Study Centres. The priority given to training under the Dementia Initiative should be continued and built upon by:

- Funding delivery of dementia specific qualifications at the Certificate IV and Diploma in Dementia Practice to create dementia champions in the workplace.
- Providing training in areas of care that have arguably been neglected and are critical to the quality of life for people with dementia, such as pain management and palliative care.
- Maintaining the effort through Dementia Training Study Centres at the tertiary level to include dementia in the training of doctors, nurses and other health professionals.

Embedding social engagement activities in the design of services helps to promote more positive relations between staff and people with dementia. It gives the services a focus of activity for people with dementia – something to look forward to. Many of the programs operated by the state and territory members of Alzheimer's Australia - such as Memory Cafes, friendship clubs, music and art therapy programs, the Living With Memory Loss Program and centres providing overnight care and outreach activities - all have as their common purpose enabling people to continue their lives for as long as possible and as normally as possible.

Equally, in residential care activities that provide social engagement and self worth have an important part to play.

Conclusion

There have been dramatic changes in social attitudes to dementia and in better understanding how to respond to the needs of people with dementia. The 2005 Budget Dementia Initiative was a landmark decision for people living with dementia. But there will be few people currently living with dementia who do not continue to feel the stigma and social isolation that dementia attracts. We have a real challenge to achieve a public health policy that reflects dementia as a health priority and not just as an issue for aged care. There is much to do in planning for the services and health infrastructure needed as a consequence of the doubling of the number of Australians with dementia by 2030.

Ten years ago, it would have been difficult to imagine a world in which dementia had been adopted as a Health Priority by the National Government. Having said that, there are concerns that need to be addressed, particularly in respect of primary care. Equally, unless there is a recognition at the national level of the need for reform and change in the provision of aged care, many of the changes needed to make the care system more responsive to the needs of people with dementia simply will not happen – for example in respect of graduated care packages.

The 2010 Budget will be critical for people living with dementia and there will be a need to address new priorities as well as to build on what has been achieved through the Dementia Initiative.