

Thank you for the opportunity to speak today at this important conference.

Alzheimer's Australia takes the view that the impact of dementia will make it *the* major chronic health condition of the 21st century. There are over 330,000 Australians living with dementia and this is expected to increase to be almost 900,000 by 2050. Already dementia is the third leading cause of death in this country.

Until recently, dementia was not seen as a health issue but instead as a concern for the aged care sector. I am always pleased and still a bit surprised when I am invited to speak to a health conference such as this one rather than one which is specific to ageing or aged care. I can not count the number of times over the last ten years that I wrote to a Minister for Health about a health issue only to be referred to the Minister for Ageing or the Aged Care Division. Over the 15 years I have been CEO we have seen two Health Ministers – most recently Minister Dutton.

Of course dementia should be core business for aged care, as over 50% of people in aged care facilities have dementia.

But we must also remember that 70% of people with dementia are living in the community. That means that there are over 230,000 people with dementia who are trying to access support through their primary care doctor, the hospital system or the broader community.

And the evidence suggests that the health system is in many cases failing people with dementia.

We have had some success in recent times in getting dementia on the health agenda- with the decision by health ministers to make dementia a National Health Priority Area in 2012 and funding in the 2012 aged care reforms to address dementia care in both the health and aged care system. But much more needs to be done to ensure people have access to the care they need.

Today I will focus my brief talk on four themes:

- The implications of population ageing and increasing numbers of people with dementia
- Preventative health and chronic disease
- Action required in primary care and acute care to ensure access to appropriate care
- Role of enablement and social inclusion and engagement in promoting positive ageing

DEMENTIA AND POPULATION AGEING

Australians live almost 25 years longer than Australians who lived 100 years ago. As a result of longer life expectancies the demographic profile of Australia is changing. In 2012, people over the age of 65 made up 14% of the population. By 2060 this will increase to nearly a quarter of the population.

It is of course good news that people are living longer lives. Children who were born in 2012 can expect to have an average life expectancy of 94 for females and 91 for males (Productivity Commission). But we also must be realistic about the implications for the health system.

Longer life expectancy means that people are at greater risk of developing chronic health conditions including dementia. The literature consistently suggests that the prevalence of dementia increases exponentially with age from about age 65, doubling every 5 or 6 years.

But let me be clear- dementia is not an inevitable consequence of ageing. Three in ten people over the age of 85 have dementia, which also means that 70% of people over the age of 85 are dementia-free.

But the reality is that as the number of older people in Australia increase, so will the number of people who are living with dementia.

As I said at the beginning over the next 35 years or so, it is expected that the number of people with dementia will nearly triple, from 330,000 in 2014 to nearly 900,000 by 2050. The interesting point in this slide is that more women develop Alzheimer's disease and other dementias than men in later life and that this is not just accounted for by the fact that women live longer. The reason for this is still unknown and much more research is required to fully understand why

Dementia will have a significant impact on the health and aged care budget. Total direct health and aged care system expenditure on people with dementia was estimated to be at least \$4.9 billion in 2009–10. 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. By the 2060s, spending on dementia is set to outstrip that of any other health condition and will represent around 11% of health and residential aged care sector spending.

And these numbers do not begin to describe the impact dementia has on families and people who are living with this disease. Dementia is devastating both for the person who is diagnosed as well as for their family and friends.

PREVENTATIVE HEALTH AND CHRONIC DISEASE

People often find it difficult to face these figures and feel that since there is no cure for dementia on the horizon there is little hope. But there is some good news that even if we can not cure the disease at this time, there are steps we can take to reduce the risk of developing dementia.

There is now broad community awareness that the decisions that we make in our younger life will affect our health and wellbeing as we age. The evidence suggests that 30 per cent of chronic disease could be avoided through reducing risk factors such as smoking, obesity, excessive drinking, and lack of exercise.

But understanding about dementia risk reduction is poor. In fact for most- it is limited to the notion that "brain-training" or cross word puzzles might help keep our brain healthy.

Dementia risk reduction is more than keeping our brain active. Research indicates that approximately half of the cases of Alzheimer's disease worldwide are potentially attributed to

risk factors such as Diabetes, hypertension, obesity, smoking, depression, cognitive inactivity and physical inactivity.

With Government support, Alzheimer's Australia has been able to deliver the world's first publicly-funded dementia risk reduction program – Your Brain Matters. The program is centred on the concept that it takes five simple steps to maximise your brain health:

- 1: look after your heart
- 2: be physically active
- 3: mentally challenge your brain
- 4: follow a healthy diet
- 5: enjoy social activity

People often ask whether these types of public health campaigns can make a difference. Will we really see a lower rate of dementia in future?

Two studies in the UK and Denmark suggest that changing rates of dementia might already be a reality.

They found that in England and Wales, the prevalence of Dementia over the last two decades dropped by 24 per cent among those 65 and older.

And in Denmark the percentage of the elderly over 90 whose cognitive abilities were severely impaired also dropped between 1998 and 2010.

In their interpretation the authors of the UK study said: “the scale of reduction that we identified is substantial and in line with major reductions in risk factors in higher income countries, which have been modified by societal changes such as improvements in education and prevention and treatment strategies in recent decades”.

Of course we can't say that if people do all the right things, by looking after their brain, body and heart, that they will definitely not get a diagnosis of dementia. But we can say that we now know what people can do to reduce their risk- and that there is a real possibility of reducing the numbers of people with dementia at the population level if action is taken.

ACTION REQUIRED IN PRIMARY AND ACUTE CARE

Though there is hope to reduce numbers in future of people with dementia, we must ensure the health system is working well now for the people who are living with dementia and is able to respond to the future numbers.

When I talk to people with dementia and their families they tell me the health system is not working for them. And the research supports this concern.

The average time from first experiencing symptoms of dementia to getting a formal diagnosis of dementia is 3.1 years. For people living with dementia this means years are spent wondering what is wrong and not being able to plan for the future.

There are a range of factors that contribute to this delay including GP lack of training on dementia diagnosis, concern that there is no benefit to an early diagnosis because of the lack of treatments available, lack of services available at a local level, and difficulty in access to specialists.

Similarly there is evidence that hospitals are dangerous and confusing places for people with dementia. Cognitive impairment and difficulty communicating within a busy hospital environment can lead to worse health outcomes through delays in recovery and extended lengths of stay.

Diversity can add an additional layer of complexity to an already complex disease. People from culturally and linguistically diverse backgrounds often have a different understanding of dementia, with some seeing it as a mental illness or 'madness'

When a person with dementia from a CALD background first approaches aged care services often they are at a point of crisis. They may have experienced years of delays in getting a diagnosis - evidence suggests that people from CALD communities may experience an even longer delay than the 3.1 years which is the average for the general population.

A report that we commissioned from the Australian Institute of Health and Welfare which was published last year found that people with dementia are staying in hospital longer and have higher costs of care than other patients in hospital. But perhaps the most remarkable finding in this report was that 47% of people with dementia in hospital do not have their diagnosis recorded. This is astounding given the impact dementia has on all aspects of care.

I am pleased that these issues have been taken seriously by Government.

As part of the 2012 Aged Care Reforms, Government invested \$39.2 million over five years to improve hospital care for people with dementia and \$41.3 million to support GPs to make a more timely diagnosis of dementia and to expand the scope of DBMAS into hospitals and primary care.

The Minister's Dementia Advisory Group held forums on both acute care and primary care last year which helped to identify priorities for action.

The strategies in primary care include:

- Training packages for GP's, practice nurses, and nurse practitioners. Alzheimer's Australia in collaboration with Dr Allan Shell has already delivered dementia training workshops to GPs in every state and territory. There is now a need for further roll out of training, particularly in regional and remote areas
- Developing a business case for GP's in terms of reimbursement for assessment of dementia. GPs often express concern that they do not have sufficient time to assess people for dementia and are unaware of the MBS reimbursements that they can apply
- Developing local pathways for diagnosis of individuals who show signs of cognitive impairment including referral pathways.

The strategies to improve hospital care include:

- Incorporating access to appropriate care for people with dementia into the National Safety and Quality Health Service Standards. As a result of the Ministerial Dementia Advisory Group or MDAG meeting, the Australian Commission for the Safety and Quality of Health Care has undertaken a project to develop resources to guide hospitals in how they should be ensuring quality care for people with cognitive impairment as part of the existing National Standards.
- Development of training programs for hospital staff on cognitive impairment
- Auditing the physical design of hospitals to ensure they are appropriate for people with dementia. The DTSC's have been commissioned to provide advice and information on appropriate design of hospitals for people with dementia. Workshops were held across Australia in 2013.
- Adopting a program for change approach to identifying innovative approaches and models of care to improve care of people with dementia in hospitals. Applications for funding might be sought from appropriate organisations, including hospitals, to promote good practice approaches to care to demonstrate the clinical benefits, trial efficient and effective implementation approaches, and develop and make available resources to assist other acute care facilities to implement the change in practice. This might include cost-benefit analysis of the model of care to alert the acute care sector to the potential for long term cost saving when appropriate care models are in place for people with cognitive impairment.

It is important we build on existing practice. For example, a Cognitive Impairment Identifier has been used with much success in the Ballarat Hospital to ensure the identification of people who have cognitive impairment as well as providing training to staff to ensure they know how to communicate with a person who has dementia. There have been discussions of the potential benefits of rolling out this initiative more widely and evaluating the cost effectiveness of this intervention.

Over the next 3 years we should see the further roll out of initiatives to tackle these issues. I am hopeful that this investment will lead to improvements for consumers.

In addition to new initiatives we must build on existing programs that are working well to support people who have dementia. For example, Home Medicine Reviews and Residential Medication Management Reviews have played an important role in ensuring that people with dementia are receiving appropriate medication and that interactions between medications are being considered. It is concerning to hear that the Government is putting caps on these services and potentially limiting access through periods of exclusion.

Social Inclusion

It is difficult to talk about health issues without touching on the interaction of social issues and health. Social relationships affect quality of life, mental and physical health and even mortality risk, including for those with existing medical conditions.

Often people associate dementia with memory changes and forget how it can affect behaviours, communication, and relationships.

People with dementia often find that family and friends stop calling or visiting after they hear of a diagnosis.

A study released in 2012 found that 60 per cent of those surveyed indicated that if they received a diagnosis of dementia they would feel a sense of shame, and nearly half said that they would be humiliated by the diagnosis.

Approximately 1 in 5 said they would feel uncomfortable spending time with a person who had dementia.

Alzheimer's Australia believes that promoting active social engagement in the community by people with dementia and their carers is the best way to ensure a better community understanding of dementia and also to dispel some of the myths.

Over the last 12 months or so we have been advocating for the development of dementia friendly communities. The essence of dementia-friendly communities is to give people with dementia to the maximum extent possible a purpose in life through being engaged with friends and the community and having access to services.

This is not a new idea. There are a range of excellent initiatives happening overseas including in the UK where Prime Minister David Cameron issued a challenge on dementia which included the development of dementia friendly communities.

There are a range of initiatives already underway in Australia that are beginning to address some of these issues including volunteering program, choirs, activity groups and programs for people with dementia through the National Gallery of Australia and regional art galleries in Australia. Alzheimer's Australia has developed a set of DVDs that are designed to help train emergency services and transport workers as well as others in banking and retailing in how to communicate with a person who has dementia. These can be found at isitdementia.org.au.

The goal of Alzheimer's Australia is to find ways to ensure that inclusive approaches are rolled out in communities across Australia.

The concept of dementia friendly communities is gaining grass-roots momentum. For example, in Port Macquarie, community members have developed a dementia action group made up of a broad range of community representatives including police, church, local government, and community workers who are all working together in developing a plan to create a dementia friendly community in Port Macquarie.

In the coming months, working closely with the community and people with dementia Alzheimer's Australia will be developing guiding principles for dementia friendly organisations. We will work closely with national organisations to assist them in becoming more dementia friendly and will be guided by the knowledge and experience of people living with dementia.

Conclusion

Dementia is having a major impact on our health and care system in Australia and that impact will only increase as our population ages. We need new approaches to support and care for people with dementia. It will not be enough to just invest more dollars into the same

care and support to provide more residential care places and hospital beds. If we are to be able to respond to the needs of 900,000 Australians with dementia by 2050 we will need to have creative solutions and innovative approaches to meeting their needs. We will need to utilise health promotion activities to reduce the numbers of people affected by dementia. We will need to find new pathways to diagnosis and training GPs to better understand dementia and differentiate it from normal ageing. And perhaps most importantly we will need to find ways to support people with dementia to live with the highest quality of life in the community.

Of course there is a need for Government investment in these areas but just as important are creative ideas and innovative approaches. People with dementia want to continue to have as much choice and quality of life as possible as dementia develops and we must challenge ourselves to rethink how our health system can best respond to the needs of people with dementia.