



Alzheimer's  
Australia  
Living with dementia

# Dementia: facing the epidemic

A vision for a world class dementia care system



Compiled by Glenn Rees, CEO Alzheimer's Australia  
September 2009



# **FACING THE EPIDEMIC: BUILDING A WORLD CLASS DEMENTIA CARE SYSTEM**

## **Foreword**

The vision for a World Class Dementia Care System presented in this publication is based on ten years of policy work and the views of the Alzheimer's Australia consumer advisory network.

Since 2003, a number of reports commissioned by Alzheimer's Australia from Access Economics have provided up to date prevalence figures and economic analyses of the impact of dementia on the health and care system.

Eminent Australian clinicians and researchers have collected research evidence supporting the potential for reducing the risk of dementia through changes in lifestyle.

Alzheimer's Australia has, with others, taken the lead in informing discussion about the benefits of empowering consumers through consumer directed models of care to have a greater say in deciding what services they need and when, where and how those services are provided.

A National Consumer Summit was held at Parliament House in October 2005 to identify the priorities for improving the lives of people living with dementia. Another Summit was held in February 2009 to highlight the issues faced by younger people in obtaining a diagnosis and in accessing services

There can be no doubt that there is a window of opportunity to plan now for the dementia services that 592 000 Australians will need in 2030, and to invest now in the research necessary to identify those most at risk and to delay the onset of dementia or to slow its progression.

Members of the Alzheimer's Australia consumer advisory network agree that the Dementia Initiative – Making Dementia a National Health Priority – has demonstrated progress in many areas. However, there has been no communication strategy to promote awareness of dementia, more dementia community care packages are needed and national action is lacking in key areas such as cutting edge research into the cause and prevention of dementia, early intervention and diagnosis and acute care.

I should like to thank Glenn Rees, our Chief Executive Officer for compiling this report and all those who have contributed, particularly Anne Eayrs, our National Policy Officer, and the Alzheimer's Australia National Consumer Advisory Committee, National Cross Cultural Dementia Network and the National Aboriginal and Torres Strait Islander Dementia Advisory Group.

*Marc Budge  
President*

## **From the perspective of a family carer**

It has been 16 years since my Mum was given her diagnosis of Alzheimer's disease.

There have been some very rough passages in the dementia journey for my Mum and for her family and friends. We have been lucky to have soft landings for the most part and, perhaps, have been much luckier than many others.

For several years after the diagnosis my Mum enjoyed a cheerful life living in her own home with support from the family and community services. Mum could enjoy important things in life such as going to the shops, being with friends, enjoying her garden and playing the piano in her own home, feeling secure and loved with us next door and friendly, supportive neighbours.

Recently that way of life became impossible to sustain and residential care became the choice of necessity. The decision for us, as for so many others, was agonising but the reality was made easier by the necessity.

Our experience confirms the experience of so many others. It is simply very hard to find residential care services that are able to provide good quality dementia care. It is a traumatic and difficult process to get advice on what residential care services may be appropriate and offer a good standard of care. And it is worse still to find an appropriate service only to find that it has no available place.

Throughout the journey with my Mum we have tried to avoid succumbing to despair and to continue to engage constructively. Focusing on positives and what is possible despite the impacts of the condition is the only way to maintain any joy in life.

Family carers cannot afford to become overwhelmed by dementia. One has to face it. In the wider community domain, we all need to face it – the support and care options in place will critically affect the health and wellbeing of millions of Australians.

This publication argues that systemic change throughout the health care system to provide better care for those with dementia and the other health conditions they may have is the only way forward. It is, I feel, an excellent contribution to a public discussion that may not be sexy, but is URGENT!

The need is to take action now in planning for a health care system that responds flexibly to the unique needs of each person with dementia and their family carers.

My Mum has shown that living with Alzheimer's doesn't mean the end of life or the need for love, understanding and social engagement. All those with a diagnosis of dementia should have that right.

*Sue Pieters Hawke*

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## EXECUTIVE SUMMARY

Australia needs a new vision and increased Australian Government commitment to build the world class dementia care system needed to face the dementia epidemic.

The twin objectives of this vision are to:

- provide quality dementia care for Australians from all cultures and of all ages, regardless of where they live; and,
- reduce the prevalence of dementia in the future.

Dementia is the term used to describe the symptoms of a large group of diseases that result in a progressive decline in cognition. These include decline in memory, reasoning, communication skills and the capacity to carry out the activities of daily living. Dementia can affect anyone in society irrespective of age, gender, education, ethnicity and class.

In 2005 Australia became the first country in the world to make dementia a National Health Priority. The Dementia Initiative has achieved significant benefits from a consumer perspective.

However, the Dementia Initiative falls short of the action necessary to fully face the dementia epidemic in key areas that include public awareness, diagnosis and early intervention, acute care, prevention and equitable access to services for all Australians.

National action is necessary because:

- Dementia has an impact on every part of the health and care system.
- The number of Australians with dementia in Australia will double to 592,000 by 2030 and nearly double again to 1.13 million in 2050.
- The ageing of the population and changing family structures will lead to a higher demand on community and residential care services.
- The cost of replacing all family carers with paid carers is estimated at \$5.5 billion per annum.
- Australia faces a shortage of more than 150,000 paid and unpaid carers by 2030. The cost of dementia care in 2008 is estimated at \$5.4 billion per annum.
- 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. 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.
- Dementia is already the largest single cause of disability in older Australians (aged 65 years or older) and is responsible for one year in every six of years of disability burden for this group.
- Dementia is the fourth most common cause of death after heart disease, stroke and lung cancer.
- The risk of dementia may be reduced by lifestyle and health behaviours but 49% of Australians do not know.

Alzheimer's Australia proposes an additional investment of \$1 billion over five years to address the dementia epidemic in Australia, with an emphasis on encouraging community awareness and positive lifestyle choices, dramatically improving dementia care practice and outcomes, promoting equitable access to dementia care services and supporting cutting-edge research.

This investment will build on the \$120 million per annum in funding currently available under the Dementia Initiative, which should be continued so that the gains already made can be extended and maximised.

The Dementia Initiative has received bipartisan support, including for the continuation of the funding beyond 2009. This provides a unique opportunity to develop and support a world class, dementia care system.

## THE PROPOSAL

The greatest challenges for 2010–2014 and the next stages of the Dementia Initiative are to maximise strategic opportunities and links, and to be genuinely national in impact across Australia's health and care system. The Initiative must promote social inclusion and respond to the growing needs of people with dementia and the people and services that care for them.

At present there is inadequate recognition that dementia impacts on all parts of the health and care system – including primary care, early intervention, acute care, medication management, community care, residential care and palliative care. This is important because dementia usually presents with other co-morbidities. There is a need to prioritise dementia in the health system as well as in aged care.

There are four critical elements of this proposal for a world class dementia care system.

First, a national communications strategy to promote understanding of dementia and to reduce stigma and social isolation. *(pages 10-11)*

Second, investment in health infrastructure to achieve:

- a) a reduction in the prevalence and incidence of dementia through investment in research on the causes and prevention of dementia. *(page 12)*
- b) early intervention and diagnosis and the identification of those population groups most at risk of dementia. *(pages 12-14)*
- c) better informed Australians about the potential to reduce the risk of dementia. *(pages 14-15)*

Third, measures to strengthen quality dementia care by:

- a) promoting access to higher-order professional development and training. *(pages 15-16)*
- b) reviewing access and best practice models and expanding the Dementia Behaviour Management Advisory Services to provide advice on dementia care to community and residential care services. *(pages 16-17)*
- c) facilitating knowledge transfer to ensure evidence based practice is adopted as quickly as possible in dementia care services. *(page 17)*

Fourth, to improve access to care services by:

- a) implementing a 'dementia equity' program to assist access to mainstream services for those people from culturally and linguistically diverse (CALD) backgrounds, Indigenous people, those with younger onset dementia and those in rural and remote areas. *(pages 17-19)*
- b) enhancing support for carers and people with dementia. *(pages 19-20)*
- c) expanding the provision of care packages and respite care that respond to the needs of people with dementia and their carers. *(pages 20-21)*
- d) planning and expanding the provision of residential dementia-specific places. *(pages 21-22)*
- e) making hospitals less dangerous places for people with dementia. *(pages 22-23)*

The summary table at Attachment A indicates how the additional \$1 billion might be prioritised over five years. It is not a detailed costing, but provides an indication of the priorities of people living with dementia.

## INTRODUCTION

In the 2005 Budget, the then Australian Government introduced measures to make dementia a National Health Priority with additional funding of \$320 million over five years. Australia was the first nation in the world to adopt dementia as a National Health Priority.

Three measures were introduced under this 2005–2009 Dementia Initiative:

1. Initiatives to support dementia research and innovation, improved care and dementia prevention and early intervention (\$70.5 million over five years).
2. The introduction of 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 Dementia Initiative has received bipartisan support, including for the continuation of the funding beyond 2009. This provides a unique opportunity to develop and support a world class, integrated national system.

### What is dementia?

Dementia is the term used to describe the symptoms of a large group of conditions that result in a progressive decline in cognition. These include 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, such as depression, psychosis, aggression and wandering. These conditions may complicate care for the individual and any other co-morbidities they may have.

The causes of dementia are not well understood, but research over the last 25 years has provided a much better understanding of the changes in the brain as dementia progresses. 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 abuse and intellectual disabilities such as Down Syndrome.

Dementia does not discriminate. It can affect anyone in society irrespective of age, gender, education, ethnicity and class. National action should be designed to address the needs of all people with dementia at any age.

### Dementia: The Economic Impact

Dementia is both one of the most common and most disabling of all chronic health conditions. In summary:

- There are over 245,000 Australians with dementia with over 1300 new cases every week.<sup>1</sup>
- By 2030 there will be 592,000 people with dementia and by 2050 over 1,130,000.<sup>2</sup>
- The cost of dementia care in 2008 is estimated at \$5.4 billion per annum.<sup>3</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>4</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>5</sup>
- The opportunity cost or lost productivity born by individuals, business and government was estimated at \$881 million in 2008.<sup>6</sup>
- Dementia is the fourth largest cause of death after heart disease, stroke and lung cancer.<sup>7</sup>



- Dementia is already the single cause of disability in older Australians (aged 65 years or older and is responsible for one year in every six of years of disability burden for this group.<sup>8</sup>

The economic impact of the rapid increase in the number of Australians who will have dementia and need services in the future 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>9</sup>

## **Dementia: Social Costs**

Dementia is a social condition as well as a medical one. It attracts stigma, social isolation and personal discrimination. These compound the difficulty of the dementia journey that can take place over many years. The social and economic impact on individuals and their families can be particularly difficult for CALD and Indigenous population groups. There is a need for recognition of the impact of dementia on people with younger onset dementia, and the very different needs of the 15,000 Australians who develop this condition – sometimes in their teens, but with increasing frequency in their 30s and older.

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, caring for a person with dementia has a negative impact on the health and wellbeing of family carers. Social impacts may include loss of work and social activities. Health impacts can include depression, anxiety, stress, physical health impacts and sleep disruption. Additional stresses can occur if the family carer is older and in failing health themselves. Younger carers can also face difficulties if their working hours are reduced or if time with their immediate families is reduced due to their caring roles.

The social cost of dementia on Australian families is enormous.

- It is estimated that dementia impacts on the lives of a million Australians who provide support for people with dementia in one way or another – from helping with shopping to 24-hour care.<sup>10</sup>
- Family carers may be the only source of care for many people with dementia – around 37% of people with dementia received no formal care in 2008.<sup>11</sup>
- The cost of replacing family carers with paid carers in 2008 is estimated at \$5.5 billion per annum.<sup>12</sup>

## **The Dementia Initiative - Making Dementia a National Health Priority**

The decision in the 2005 Budget to make dementia a National Health Priority was a landmark decision not just in Australia but worldwide. Australia has led the way in acknowledging the economic and social impact of dementia and the need to plan for the epidemic. Other countries have since developed national strategies, following Australia's lead.<sup>13 14</sup>

An independent evaluation has been commissioned by the Australian Government. From a consumer perspective, the Dementia Initiative has achieved much of its promise and has shown positive returns on the investment made by the Australian Government. While some significant areas like awareness and primary care have not been comprehensively addressed, it has provided:

- An opportunity to improve access to specialist dementia services and demonstrate the potential of greater choice for consumers through access to Extended Aged Care at Home (Dementia) packages in the community.

- Increased community engagement through community grants and sector development grants and the awareness and community education activities made possible through improved funding for the National Dementia Support Program (NDSP) administered by Alzheimer's Australia.
- Much needed funding increases in dementia care research through the three Dementia Collaborative Research Centres and dementia research grants, which have increased research capacity, promoted collaboration, attracted young researchers into the field of dementia care and positioned dementia researchers to apply for NH&MRC and other major grants.
- An opportunity to improve 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 the NDSP.

Significant progress has been made and the core elements of the Dementia Initiative should be continued with the current level of committed funding of around \$120 million per annum.

However, the Dementia Initiative falls short of the action necessary to fully face the dementia epidemic in key areas that include public awareness, diagnosis and early intervention, acute care, prevention and equitable access to services for all Australians. There is also a need to better coordinate the elements of the Dementia Initiative and in particular the work of the Dementia Collaborative Research Centres and the Dementia Training Study Centres.

## PRIORITIES FOR 2010–2014

The greatest challenge for the next stage of the Dementia Initiative is for it to maximise strategic opportunities and links, and to be genuinely national in its impact across the country's health and care system. It must promote social inclusion and respond to the growing needs of people with dementia and the people and services that care for them.

At present, although significant sums are spent on dementia care through the aged care system, there remains inadequate recognition that dementia impacts on all parts of the health and care system – including primary care, early intervention, acute care, medication management, community care, residential care and palliative care. This is important because dementia usually presents with other co-morbidities. There is a need to prioritise dementia in the health system as well as in aged care.

The delivery of better access to quality dementia care will depend on fundamental changes in the delivery of health care and government decisions on the final report of the National Health and Hospital Reform Commission. Alzheimer's Australia welcomes the directions proposed for greater choice for older Australians and the priority for mental health given the importance of depression among those living with dementia and the poor access to services for those with dementia and psychiatric conditions. But this action in itself will not be enough to address the challenge of reducing the prevalence of dementia or the deficits from the past in dementia care services faced as Australia is with the growing numbers of people with dementia.

**The twin objectives of the new national strategy must be to improve the equitable provision of quality dementia care for Australians from all cultures and of all ages, regardless of where they live, and to reduce the prevalence and incidence of dementia in the future.**

Alzheimer's Australia proposes that the new vision for a world class dementia care system requires additional measures to:

- i) Increase public and professional awareness to reduce the stigma associated with the condition.
- ii) Build health infrastructure to reduce the prevalence and incidence of dementia and to achieve early intervention and diagnosis.
- iii) Improve the quality of dementia care.
- iv) Improve access to care services.

Each of these elements is developed below.

### **i) Increased awareness and reduced stigma**

Consumers believe that true social inclusion and improvements in dementia care are only going to be achieved when the general population openly acknowledges dementia as a condition that does not need to be feared. Greater community awareness has played a part in fostering more positive community attitudes to cancer and depression.

The stigma and social isolation that result from dementia can be attributed to the commonly held view that dementia is a natural part of ageing, the absence of a 'cure' and the debilitating nature of the condition. A community awareness campaign is needed that fosters a climate of open discussion of dementia and a greater awareness of the nature of the condition, the positives of early diagnosis and social connection, quality dementia care and the potential of dementia research to find medical solutions as has been done for other chronic diseases.

The UK National Dementia Strategy<sup>15</sup> identified some emerging key messages for a national public information campaign:

- Dementia is a chronic condition.
- Dementia is common.
- Dementia is not an inevitable consequence of ageing.
- The social environment is important, and quality of life is as related to the richness of interactions and relationships as it is to the extent of brain disease.
- Dementia is not an immediate death sentence; there is life to be lived with dementia and it can be of good quality.
- There is an immense number of positive things that we can do – as family members, friends and professionals – to improve the quality of life of people with dementia.
- People with dementia make, and can continue to make, a positive contribution to their communities.
- Most of us will experience some form of dementia either ourselves or through someone we care about.
- We can all play a part in protecting and supporting people with dementia and their carers.
- Our risk of dementia may be reduced if we protect our general health, such as by eating a healthy diet, stopping smoking, exercising regularly, drinking less alcohol and generally protecting the brain from injury.

The awareness campaign should also be targeted at health professionals to increase awareness of the importance of early intervention, including accurate diagnosis and timely referral to community services.

**Action: A community awareness campaign to promote a better understanding of dementia and to reduce stigma is proposed at a cost of \$13 million in 2010–2014.**

## **ii) Health infrastructure**

Investment in health infrastructure is essential to achieve three goals.

- a) A long-term reduction in the prevalence and incidence of dementia through investment in research directed to better understanding the causes of dementia and its prevention.
- b) Early intervention through improvement in diagnosis and management and identifying those population groups most at risk of dementia.
- c) Increased public awareness that the risk of dementia may be reduced through brain health and lifestyle changes.

### **a) Measures to reduce the prevalence and incidence of dementia**

Investment in dementia research has increased in recent years, in part as a consequence of the Dementia Initiative. Nevertheless, dementia research in relation to health and care costs, disability burden and prevalence is underfunded in relation to other major chronic diseases. Based on average annual Australian research funding over 2002–2007, it has been estimated (2008) that annual expenditure on dementia research was about 50% of research funding relative to cancer; 30% of research funding for cardiovascular disease relative to the current cost of care and 20% of research funding for cancer and diabetes, relative to the current direct cost of care.<sup>16</sup>

The National Health and Medical Research Council currently spends about \$22 million per annum on dementia research. Cancer attracts nearly \$160 million, cardiovascular disease around \$110 million and diabetes over \$60 million.<sup>17</sup>

There is a need for increased priority and targeted funding to support basic research to:

- better understand the causes of dementia,
- develop medical interventions that delay the onset of dementia,
- build on the evidence base that shows the risk of dementia may be reduced through lifestyle changes; and,
- identify those most at risk of developing dementia.

In five to ten years time, it is possible to envisage a world where:

- Those population groups most at risk of dementia can be identified.
- There are medical interventions to delay the onset of dementia and slow the progression of dementia.
- There are more data to demonstrate that lifestyle choices including psychological well being and nutrition can delay the onset of dementia.

The benefits of even a short delay in the onset of dementia will be substantial. It has been estimated that if the onset of Alzheimer's disease (50-70 per cent of all cases of dementia) could be delayed by five years, it would reduce the numbers of those with Alzheimer's disease by half (between 2000 and 2040) with significant savings to the health and care system.<sup>18</sup>

**Action: An additional investment is proposed of \$220 million in dementia research during 2010–2014 through the National Health and Medical Research Council with the objective of establishing a target of 1% of the care costs of dementia (about \$50 million per annum).**

#### ***b) Early intervention and diagnosis***

Research commissioned by Alzheimer's Australia indicates that over 90%<sup>19</sup> of all Australians say they would be likely to visit their GP if concerned about their memory. At the same time, there is evidence that many GPs have difficulty in identifying and/or addressing dementia through appropriate referral to specialists and support services.

- Currently only about one-third of people with dementia receive a formal diagnosis at any time in their illness.<sup>20</sup>
- The gap between first symptoms and diagnosis ranges between 10 and 32 months.<sup>21</sup>
- Up to 90% of mild dementia cases go undetected in general practice.<sup>22</sup>
- Barriers to the early diagnosis of dementia and diagnostic disclosure in primary care include:
  - stigma and negative attitudes to dementia care
  - difficulties in differentiating normal ageing from dementia
  - GPs lack of confidence or training and risk of misdiagnosis
  - the paucity of specialist diagnostic services, especially in rural areas
  - limited time and lack of a recognized, time-efficient screening tool
  - a perceived lack of need to determine a specific diagnosis
  - perception that the patient cannot comprehend/cope with the diagnosis
  - risk of damaging the doctor-patient relationship.<sup>23</sup>

Better access to earlier intervention through improvement in diagnosis, assessment and ongoing management is essential because it:

- Provides the opportunity for people with dementia and their families and carers to make informed plans, including for their financial, legal and future care arrangements.
- Removes the uncertainty and trauma that comes with the delays many experience in the accurate diagnosis of dementia, particularly those with younger onset dementia.

- Assists with the targeting of support to those who need assistance within the health care system or are at risk of health complications.
- Allows carers to access support that can reduce their health risks and the associated costs for individuals and governments.

Good quality dementia management is multifaceted and fits well with the complex and chronic care model. Also, most people with dementia – and many family carers – are older and have multiple co-morbidities such as hypertension, diabetes, depression and arthritis. Management of co-morbidities may be complicated by the presence of dementia, resulting in poorer individual and system health outcomes.

People with dementia benefit from active case management<sup>24</sup> within general practice. Practice nurses and other health professionals, like community nurses and psychologists, have an important role to play in ensuring cognitive impairment due to dementia or depression is correctly identified at an early stage, and that access to appropriate community support is facilitated.

People with dementia and their families and carers are seriously concerned about the inability of the current primary care system to accurately diagnose/identify dementia in a timely way and to provide support and referral.

The principal actions needed are to:

- Promote existing Australian Government support mechanisms that can be used to better support people with dementia and their family carers, such as the Medicare items available to support complex and chronic care. (This could be part of the education package.)
- Ensure appropriate funding models are in place to reimburse health professionals for the additional time they spend with family carers due to their care roles, and to enable the employment of practice nurses to support active management of patients with dementia including, as appropriate, undertaking regular assessments and community referral.
- Implement a dementia education and training package, including case detection, for primary care professionals across Australia to increase earlier detection and diagnosis in general practice and other primary care settings.
- Foster a multidisciplinary approach including by providing better access to specialist services for people with dementia at any age.
- Improve access to specialist advice including through communication approaches such as telehealth and eHealth.
- Work with relevant vendors and providers to ensure that medical software is used to prompt primary care professionals to consider dementia risk as people age or where relevant co-morbidities exist, as well as link people with dementia and their family carers with the information and support that they need as dementia progresses.
- Develop and implement updated national guidelines for best practice dementia assessment and care for use by the various professions.
- Invest in infrastructure to develop centres of excellence in the diagnosis and ongoing management of people with dementia in every jurisdiction.

These actions should be complemented by encouraging consumers to make advanced care directives, and for health professionals and the legal system to recognise them.

**Action: An investment in early intervention of \$240 million during 2010–2014 is proposed to implement the proposed actions.**

### **c) Risk reduction**

There is now good evidence to support the view that lifestyle changes may reduce the risk of dementia for some people. The evidence base is being further developed by the Dementia Collaborative Research Centre on Prevention, in which Alzheimer's Australia Vic is a partner. Market research commissioned by Alzheimer's Australia demonstrates that 50% of Australians are unaware that they may be able to reduce their risk of dementia.

Among those who are aware that it is possible to reduce the risk of dementia, there is limited understanding of the full range of potentially positive changes in health habits. For example, even after prompting, around 40 percent did not agree that reducing blood pressure or high cholesterol would help.<sup>25</sup>

Alzheimer's Australia has developed and successfully implemented the first stage of the Mind Your Mind® public education program. This public education program needs to be extended to CALD and Indigenous populations, as well as to a broader geographic audience across Australia. The program aims to increase awareness of dementia risk reduction and an investment in this approach may contribute to reducing the numbers of those with dementia.

**Action: A public education campaign based on Mind Your Mind® to be funded at a cost of \$4 million in 2010 – 2014.**

### **iii) Measures to strengthen quality dementia care**

Every individual with dementia is unique and there is no single or standard approach to dementia care – no “one size fits all” set of practices. The quality of dementia care is likely to be high if it is driven by a person-centred care approach that incorporates a partnership between service providers, the person with dementia and the family carer, and a service environment characterised by strong leadership and supported by the adoption of best care practices.<sup>26</sup>

The different individual needs of each person with dementia and their family carers necessitate a flexible and responsive approach to care services. Alzheimer's Australia has advocated that this could be achieved through adopting the consumer directed care model in care packages and respite care so that it is the consumer, if they wish, who determines the services needed and how, when and where they will be provided.

Overseas evidence suggests that the more responsive and flexible service responses that are made possible in consumer directed care models may benefit people from diverse backgrounds, who can then make better use of their own networks and ensure cultural appropriateness in the delivery of services.<sup>27</sup>

While some progress has been made in developing an education pathway through the funded Dementia Training Study Centres, more remains to be done if people with dementia and their family carers are to be well supported by an informed and educated health and aged care workforce.

It is proposed that strengthening quality dementia care should be addressed in three ways:

#### **a) Dementia Workforce Strategy**

There is wide agreement about the major issues that face the aged care workforce such as pay levels, conditions and perceived negative status. These issues require attention in the context of the reform of aged care. The focus in the Dementia Initiative must be on developing an aged care workforce that is able to deliver high quality dementia care.

An important emphasis of the Dementia Initiative to date has been on workforce training, including through the National Dementia Support Program, Dementia Care Essentials and the Dementia Training Study Centres. Alzheimer's Australia strongly supports the continuation of this core activity, but also recognises the need to 'raise the bar' for Australia's care workforce through access to higher-order professional development and training.

Alzheimer's Australia proposes that funding should be increased to:

- Provide ongoing "base level" Dementia Care Essentials training to maintain an acceptable level of care workforce skills, after reviewing for consistency, quality and minimum standards against new unit requirements.
- Extend Dementia Care Essentials training access to people who require refresher courses to provide regular reinforcement.
- Support sustainable 'special needs' dementia education and information programs in Indigenous and CALD communities.
- Implement programs to trial and evaluate the delivery of existing multimedia resources for dementia education through e-learning technologies, including online, video and teleconferencing approaches.
- Deliver Certificate IV and Diploma in Dementia Practice to promote access to higher order professional development and training, providing a sustainable career pathway for dementia specialists.
- Promote training to complement the Certificate IV and Diploma in areas of practice that are critical to the quality of life of people with dementia including:
  - cultural competence
  - pain management
  - palliative care
  - appropriate non-pharmacological and pharmacological management of behaviours of concern
  - recognition of depression and anxiety
  - stress management for professional and family carers
  - evaluation of dementia care practices.

**Action: An additional investment is proposed in the dementia workforce of \$28 million in 2010–2014 to address these priorities.**

***b) Dementia Behaviour Management Advisory Services (DBMAS)***

The implementation of these new services has been slow, but, nonetheless, Alzheimer's Australia believes that they are proving the value of the concept of providing much needed clinical advice to community and residential service providers on the management of the Behavioural and Psychological Symptoms of Dementia (BPSD).

The new services combine important elements that are much needed within the Dementia Initiative, namely expertise in dementia care and the translation of knowledge to service providers in both the management of individual cases and through training and seminars. In those states where the services are contracted to Alzheimer's Australia they form an important part of a suite of integrated services with those services provided under the National Dementia Support Program.

There is a need to review the adequacy of access to DBMAS in different parts of Australia and to compare the effectiveness of the different models that have emerged.

**Action: To review access to the Dementia Behaviour Advisory Services and the most effective delivery models and to increase the capacity of the DBMAS' services over 2010-2014 with additional funding of \$14 million.**



### **c) Knowledge transfer**

The uptake of evidence at the level of medical and biomedical research generally is inadequately carried through in medical practice, care and policy.<sup>28</sup> There is not optimal use of the available knowledge to improve the standards of health care and to make the most efficient and effective use of health expenditures.<sup>29</sup> This does not support people with dementia and those who care for them.

Alzheimer's Australia is establishing a National Quality Dementia Care Network that will have the key objective of improving the quality of dementia care through the rapid dissemination and uptake of research evidence via the various mechanisms of knowledge transfer. This is to be achieved through better collaboration between dementia care researchers, consumers and service providers.

Examples of dementia care issues where current research outcomes have not been taken up include pain management strategies, how to minimise the use of medical restraint and developments in palliative care.

The Network is planned to start later in 2010.

**Action: To build up the National Quality Dementia Care Network, total funding of \$3 million over 2010–2014 is proposed to supplement the funding raised by Alzheimer's Australia from the Wicking Trust and other sources.**

### **iv) Measures to improve access to care services**

#### **a) Dementia equity program**

A key objective of the next Dementia Initiative should be to ensure that there is an equitable distribution of mainstream funding for dementia services to all Australians from all cultures and all ages no matter where they live.

In 2009, some 97,000 (39%) of people with dementia live outside the capital cities. There are around 520 new cases of dementia in these areas every week. Prevalence outside the capital cities will grow to 241,000 in 2030 and nearly 450,000 in 2050. The number of new cases per year will grow to 76,000 in 2030 and 153,000 in 2050.<sup>30</sup>

It is predicted that in 2026 about 21% of Australians aged 65 years and over (940,000) and 25% of those 80 or older (270,000) will have been born in a non-English speaking country. While a quarter of the group 65 or older over are predicted to speak English as their main language at home, 73% will not. Some 39% are predicted to be Catholic, 7% Greek Orthodox and 5% Buddhist.<sup>31</sup>

Currently some 14% of Australians with dementia – around one in seven or 35,000 people – do not speak English at home. The proportion is projected to remain relatively high to 2050. This means that there will be 62,000 non-English speaking people with dementia by 2030 and 120,000 by 2050. The number of new cases per year for this group will be 17,000 in 2030 and 35,000 in 2050.

There is evidence to show that the language most recently acquired is lost first for people with dementia. There is also evidence that people from non-English speaking backgrounds may present later to services for a range of social and cultural reasons.<sup>32</sup>

Common issues that affect CALD communities include:

- Lack of knowledge about dementia and its symptoms and causes.
- Variations in perceptions of dementia.

- Stigma associated with dementia or lack of understanding of dementia, resulting in people being marginalised and isolated from their own communities.
- Late diagnosis of dementia, often at crisis point, due to lack of knowledge about the early symptoms of dementia, where to go for help or being ashamed of being labelled.
- Communication problems caused by many people from CALD backgrounds having low literacy levels in English language and also in their own language.
- Lack of knowledge or acceptance of the service system by members of CALD communities who are often unfamiliar with dementia services and aged care services in general as well as how to access them, often due to either language barriers or a lack of culturally appropriate services.<sup>33</sup>

The concerns to be addressed for people with dementia from 'special need' populations are that:

- The awareness of dementia is low in many CALD and Indigenous population groups. In part, this is a result of differing health beliefs and perceptions about dementia but may also be attributable to the inequitable distribution of existing funding for dementia services.
- There is evidence that the prevalence rates of dementia among remote and rural Indigenous people could be four to five times higher than those in the Australian community generally. New service models will be needed for this group. There is no comparable evidence yet for urban populations.<sup>34</sup>
- The Younger Onset Dementia Summit convened by Alzheimer's Australia in February 2009 demonstrated the special issues that face younger people with dementia (those under 65 years). While this group faces many special problems, the key to improving their quality of life and that of their families and carers is through reducing stigma, and encouraging early diagnosis and access to services that are appropriate for younger people.<sup>35</sup>
- Those who live alone or are homeless or at risk of being homeless may have special needs which merit targeted approaches.

To achieve greater equity, a three-pronged approach is proposed. First, to address the inequity of distribution of current dementia spending by having a funding pool that can be used to promote access to dementia services by different groups. Secondly, to provide funding to promote partnerships between CALD and Indigenous organisations and Alzheimer's Australia to more effectively engage these communities. Thirdly, to commission a study through the Australian Institute of Health and Welfare of access by people from CALD and Indigenous backgrounds to aged care services, including dementia services.

**Action: \$80 million be provided to enable greater equity in access to mainstream dementia services to special populations including CALD and Indigenous communities, people with younger onset dementia, those living alone and the homeless. Of that amount, \$5 million should be made available in 2010 – 2014 to resource and extend partnerships between Alzheimer's Australia and CALD and Indigenous groups.**

#### ***b) Support for people living with dementia***

The National Dementia Support Program (NDSP) plays a unique role in providing support to people with dementia and their family carers through the provision of world class information resources, skilled dementia counselling, support groups, education and training for both carers and care workers, early intervention strategies such as Living With Memory Loss programs, and both centre-based and outreach support programs.

It also provides an essential, widely accessible entry point to services and support through the National Dementia Helpline, which is operated by Alzheimer's Australia in each State and Territory. The NDSP, administered by Alzheimer's Australia is an integral part of delivering the Dementia Initiative because it:

- Provides a national focus for promoting greater awareness of dementia and consistency in the provision of core services.
- Enables Alzheimer's Australia to provide feedback on the views of people living with dementia to the Department of Health and Ageing.
- Promotes innovation and demonstration of new services through knowledge transfer in training and publications.
- Builds on the extensive experience and willingness of Alzheimer's Australia's State and Territory member organisations to collaborate at both a National and local level.
- Links with the leadership and partnership roles that Alzheimer's Australia organisations play in respect of the Dementia Training Study Centres, Dementia Behaviour Management Advisory Services and Dementia Collaborative Research Centres.

Evaluations during the life of the NDSP (and its predecessor programs) have shown it to be cost effective in the provision of helpline and counselling assistance.<sup>36</sup>

The NDSP has also been assessed as being effective in the provision of carer education by assisting carers, for example, to better use respite care and at an earlier stage.<sup>37</sup> It was also found to be effective in reducing stress for both the person with dementia and their carer by providing structured information and support through the Living with Memory Loss program.<sup>38</sup>

Significant investment has been made in the NDSP in recent years. The program is well established and supported by consumers.<sup>39</sup>

**Action: The NDSP has a critical part to play in both the delivery of core services and promoting innovation and awareness. Resources for NDSP should be increased by \$52 million in 2010–2014 to respond to the growth of the numbers of people with dementia of 16 per cent and to promote innovation in areas such as developing the concept of a support worker for those living alone or with younger onset, social engagement, restorative care therapies, safe to walk devices and deliver a new Certificate IV and Diploma in Dementia Practice.**

### ***c) Community care***

Research indicates that 60% of people with dementia live in the community, of whom 37% receive no formal care.<sup>40</sup> Family carers are a critical component of the dementia care 'workforce', providing the larger part of the care and support required for people with dementia. In the absence of family carers the Government would face a crisis in both finding and funding the necessary workers to care for people with dementia in the community.

Caring for someone with dementia is physically and emotionally draining. Carers become socially isolated and often their own health deteriorates. Significant numbers of carers are forced to stop caring because of illness or injury, which in turn leads to an increased burden on government-funded health, social and economic services and systems.

This heightens the importance of support at a community level including ongoing access to both planned and emergency respite services. For many family carers the demanding task of providing dementia care will only be sustainable with the support of community care services that respond to their needs and those of the person with dementia. A recent survey of family

carers by Access Economics <sup>41</sup> shows that service options which include home support services (such as shopping, transport and cleaning) and respite care are the most highly valued by this group.

The barriers to the provision of continuous, consistent, reliable and flexible dementia care services which are so critical to family carers as dementia progresses are:

- The current community care system offers little flexibility between program types to support care across the continuum. There is a need for graduated care packages to fill the evident gap between the CACP and EACH packages.
- The inadequate number of EACH and EACHD packages means that the stress experienced by carers is increased, and consequently many people with dementia may enter residential care prematurely.
- Inflexible program boundaries complicate a flexible and consistent response to the support needs of people living with dementia.
- The need to adopt consumer-directed models of care to give those living with the dementia the option of deciding what services will enable individuals to live as independently as possible for as long as possible in the setting of their choosing.

There is a particular need for specialist dementia respite care services that respond flexibly to the needs of both people with dementia and their family carers at any stage of the dementia journey.

Alzheimer's Australia has recommended major changes in the provision of respite care in the recent publication, *Dementia and Respite Care: "More than just a short break"*. Respite services are not only needed to provide necessary support for the family carer but to respond to the needs of people with dementia for age- and culturally appropriate social engagement.

Respite care accommodation services are needed that provide greater flexibility in the length of time for which people with dementia can be supported in community and/or residential settings, in particular, to support working family carers

**Action: An increase in the number of dementia-specific care packages and additional funding for new specialist dementia respite services are proposed, totalling \$266 million during 2010–2014.**

#### **d) Residential care**

Almost 50% of residents in residential care facilities have a diagnosis of dementia <sup>42</sup> and many more have cognitive impairment. Permanent residential care plays a significant part in the dementia care continuum because of the demanding nature of the care. As a consequence, there is a need for high levels of dementia training in all residential care services.

Most people with dementia should be able to be accommodated within mainstream residential care services providing that the staff have the necessary skills and the physical environment of the facility meets the special needs of people with dementia. Others may need specialist care in dementia specific facilities or case management by a specialist team at some point in their dementia journey, for longer or shorter periods, depending on their needs.

The introduction of the Aged Care Funding Instrument incorporating a behavioural supplement was a welcome recognition of the special demands of dementia care and the requirement for additional funding. It will be important to fully assess the impact of the ACFI on the funding of residential care services for people with dementia.

Measures that could be taken to improve the quality of care in residential care services are:

- A dementia focus in the review of the Aged Care Standards, accreditation processes and development of quality indicators. Consumers need more information about the capacity of residential care providers to provide good quality ongoing dementia care and the outcomes they are achieving.
- Dementia training for Aged Care Assessment Teams as part of their ongoing professional development to ensure that people who are assessed for residential care are advised on the most appropriate care for their condition.
- Extending current Government initiatives to improve primary health care access for people in residential care.
- The allocation in every health region of dementia specific care places that provide accommodation and care for those with severe BPSD. It has been estimated that 20,000 places are necessary across Australia.<sup>43</sup> There are no reliable data on the number of places available. Through the planning and allocation of residential care beds, planning should be made for dementia specific places to ensure equitable access.
- The funding of more places to accommodate those who have both dementia and psychiatric issues. While this problem has been recognised and highlighted by the Australian Government, there is a need for joint action by all state and territory governments to produce a national solution to ensure that this group does not fall between the cracks of aged care on the one hand and mental health services on the other.

**Action: Funding of \$60 million in 2010–2014 should be available to implement these measures in addition to the funding available through the residential care program.**

#### **e) Acute care**

Acute care remains a dangerous setting for people with dementia – and potentially more so for people whose dementia has not yet been formally diagnosed. Even if diagnosed, the diagnosis and its implications may not be set out clearly in their hospital notes and staff may be unaware or unwilling to provide the additional attention required.

In Australian hospitals, up to 50 percent of all patients admitted have some degree of cognitive impairment. Impaired mental status is the most commonly identified factor in patients who fall while in hospital.<sup>44</sup>

Delirium and dementia are associated with an increased length of stay in hospital, increased morbidity and poor prognosis. The effect of a hospital stay is very often detrimental to a person with dementia and its impact is felt well after discharge.

While admissions are less commonly made for dementia complications, many people with dementia are admitted for treatment of their other medical conditions. US data indicate that among older people with dementia, 30% also have coronary artery disease, 28% have congestive heart failure, 21% diabetes and 17% chronic obstructive pulmonary disease.

Better outcomes for people with dementia, as well as less burden on hospital staff, can be achieved via an approach which:

- Minimises unnecessary hospital admissions for people with dementia including through encouraging advanced care planning, making services available outside emergency departments and up-skilling staff in residential care.
- Recognises the need of people with cognitive impairment for support and to feel secure

in a strange environment. This might involve support for the family carer and advocacy and support arrangements for people who do not have a carer.

- Improves in-hospital practice through better recognition of cognitive impairment at admission and improved access to specialist dementia programs and specialist support for people with dementia with co-morbidities. Ongoing recognition during a hospital stay could be achieved through use of a symbol for cognitive impairment, an approach which has been recommended by people living with dementia.
- Results in a national approach to dementia care standards in acute care and a requirement for a dementia policy and its implementation within hospital accreditation processes.
- Reviews the impact of dementia as a co-morbidity on hospital funding based on diagnosis-related groups.
- Strengthens dementia education/training requirements for both clinical and ancillary staff including in areas like communication and carer involvement.

**Action: Federal funding of \$20 million in 2010–2014, matched by the state and territory governments, to implement a national program of action to improve the care of people with dementia in acute care.**

## **CONCLUSION**

A new vision is needed to build a world class dementia care system. The twin objectives would be to provide quality dementia care for Australians from all cultures and of all ages, regardless of where they live and to reduce the prevalence of dementia in the future.

The Dementia Initiative has delivered significant benefits from a consumer perspective. The challenge now is for the Initiative to become genuinely national in its impact on all Australians living with dementia and across the country's health care system.

## ATTACHMENT A

### Consumer Priorities for Additional Funding in 2010-2014

	\$ million					
	2010/11	2011/12	2012/13	2013/14	2014/15	Total
<b>Measure 1 – Stigma and Awareness</b>						
Dementia Community Awareness Campaign		4	4	5		<b>13</b>
<b>Measure 2 – Health Infrastructure</b>						
Dementia Research	30	40	50	50	50	<b>220</b>
Early Intervention and Diagnosis	30	30	60	60	60	<b>240</b>
Risk Reduction (Mind your Mind)	1	1	1	1		<b>4</b>
<b>Measure 3 – Quality Dementia Care</b>						
Dementia Workforce strategy	4	4	6	6	8	<b>28</b>
Dementia Behaviour Management Advisory Services		2	4	4	4	<b>14</b>
Knowledge Transfer	1	1	1			<b>3</b>
<b>Measure 4 – Access to Services</b>						
Dementia Equity Program	6	11	16	21	26	<b>80</b>
Support for People Living with Dementia	6	9	11	13	13	<b>52</b>
Community Care	26	60	60	60	60	<b>266</b>
Residential Care	5	10	15	15	15	<b>60</b>
Acute Care		5	5	5	5	<b>20</b>
<b>Additional Funding</b>	<b>109</b>	<b>177</b>	<b>233</b>	<b>240</b>	<b>241</b>	<b>1000</b>
<b>Dementia Initiative Commitment</b>						
Ongoing funding	120	120	120	120	120	<b>600</b>
<b>Total Funding</b>	<b>229</b>	<b>297</b>	<b>353</b>	<b>360</b>	<b>361</b>	<b>1600</b>

Note: This table indicates how the additional \$1 billion might be prioritised over 5 years. It is not a detailed costing, but provides an indication of the priorities of people living with dementia.

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### Other Papers

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