



**Alzheimer's
Australia**
Living with dementia

2012 Budget Submission

September 2011

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Introduction

Dementia is the major chronic disease of the 21st century. The Federal Government must invest in decisive action to address dementia now to improve the quality of dementia care and reduce the future numbers of people with dementia

In the 2012 budget, Alzheimer's Australia proposes the implementation of a 5 year Dementia Action Plan including:

- Commitment to the staged implementation of the reform of aged care and an acknowledgement that a plan to address the needs of individuals with dementia must be at the heart of the reforms.
- Coordinated action to address dementia as a major chronic disease through additional funding of \$500 million over five years which could be administered through a dementia focus in the flexible funds. This funding would be additional to the current funding for those elements that are subject to contractual arrangements terminating in 2013.

Funding details are set out in Attachment A.

This investment would be used to:

1. Promote awareness of dementia
2. Achieve timely diagnosis of dementia
3. Provide quality dementia care in community, residential and acute settings
4. Reduce the future numbers of people with dementia
5. Make Australians aware they may be able to reduce their risk of dementia.

In the recent 2011-2012 budget, the Government made decisions which restructure funding for programs through the Department of Health and Ageing into eighteen 'flexible funds'. This decision has terminated the **Dementia Initiative – making dementia a national health priority** although funding for some elements of the Initiative will continue to end June 2013. As a result of this decision there will no longer be guaranteed ongoing funding for valued services, the recognition of dementia as a health priority, and capacity to plan for the future delivery of dementia services.

The flexible funds have been presented as a new opportunity for a holistic approach to addressing dementia which includes awareness, primary care, risk reduction, and research as well as the traditional focus in aged care. This could be achieved through funding a Dementia Action Plan across the flexible funds.

An investment of \$500 million over five years in this coordinated approach would lead to improved outcomes for individuals with dementia and their families by:

- Reducing the stigma and social isolation that results from dementia
- Reducing the time between the first signs of memory loss to diagnosis
- Improving access to quality dementia care and support services
- Reducing the future number of people with dementia
- Reducing the risk of dementia for Australians.

The Government's commitment to Aged Care Reform and the release of the recommendations of the Productivity Commission provide a unique opportunity for action on dementia. Dementia is the core business of aged care and an aged care reform response that does not have a dementia response at its heart will not be successful. A comprehensive response to address dementia will have impacts on a number of other areas including palliative care, prevention, primary care, research and hospitals.

Within the proposed Dementia Action Plan, Alzheimer's Australia should be provided with a five year funding agreement to reduce the administrative burden and to facilitate the planning and delivery of an integrated suite of services including the National Dementia Support Program and the National Dementia Helpline.

Recommendations

The Government should act to implement aged care reform in the 2012/2013 budget and to ensure it has a focus on dementia by implementing a Dementia Action Plan to address dementia across the health care and aged care sectors.

The Dementia Action Plan should include:

1. A two year \$15 million information campaign to tackle community ignorance of dementia. This funding could be sourced from the **Chronic Disease Prevention and Service Improvement Fund** which currently includes some community awareness programs. This campaign would include social marketing, national advertising, community engagement, and education activities to raise awareness about dementia.
2. Investment of \$53 million over five years to address barriers to timely diagnosis by employing specialist dementia nurses and providing training and education programs for doctors and practice nurses. Funding for this approach could be included in the **Practice Incentives for General Practices Fund** or the **Health Workforce Fund**. This should be supported by two additional actions:
 - Bring the Department of Health and Ageing together with medical and consumer stakeholders to determine strategies to achieve timely diagnosis.
 - Link diagnosis and management of dementia into the current health reform process by acting on the strategies identified through the reform of Primary Care and mandating that Medicare Locals include diagnosis and management of dementia as part of their reporting framework and needs assessment.
3. Investment of an additional \$22 million in the National Dementia Support program to respond to increased demand in services, to provide better support services for individuals in regional and remote areas and to create innovative services which address the changing needs of individuals with dementia and their carers. This program could be funded under a single agreement through the **Aged Care Improvement and Healthy Ageing Grant Fund, Single Point of Contact for Health Information, Advice and Counselling Fund, the Aboriginal and Torres Strait Islander Chronic Disease Fund and the Rural Health Outreach Fund**.
4. Investment of an additional \$30 million in the Dementia Behavioural Advisory Services over the next five years to assist informal and formal carers to better manage the Behavioural and Psychological Symptoms of Dementia. The funding for this program would come from the **Aged Care Improvement and Healthy Ageing Grant Fund**.
5. Develop systems to make hospitals safer places for people with dementia by increasing recognition of those with dementia and improving coordination and support systems. An investment of \$41 million over five years could be funded through the **Health System Capacity Development Fund**.

6. The Commonwealth should build on the existing National Quality Dementia Care Initiative to promote the rapid uptake of research into practice in order to support high quality evidence based dementia care \$1 million pa for project funding. This program could be funded through the **Health System Capacity Development Fund and/or Aged Care Service Improvement and Healthy Ageing Grants Fund**.
7. Sustainable funding for the Dementia Training Studies Centres and the Dementia Care Essentials and bridging the gap in dementia training programs by increasing funding by \$20 million over five years. This program could be funded through the **Aged Care Workforce Fund**.
8. Investment to develop appropriate services for people with younger onset dementia. This could be funded through the **Aged Care Service Improvement and Healthy Ageing Grants Fund**.
9. Investment to develop appropriate services for people with severe behavioural and psychological symptoms of dementia. This could be funded through the **Aged Care Service Improvement and Healthy Ageing Grants Fund**.
10. An additional \$40 million investment per year into dementia research through the **National Health and Medical Research Council (NHMRC)**. This would be equivalent to a total research spend of about 1% of the total cost of dementia care.
11. Funding for a \$4 million public education campaign to make Australians aware that they may be able to reduce their risk of dementia both by management of other chronic diseases which increase the risk of dementia (e.g. stroke, diabetes, obesity) and by changes in lifestyle including social and mental activity, nutrition and physical exercise. This program could be supported through the **Health System Capacity Development Fund** which already supports a number of preventive health programs or it could be funded through the **National Preventive Health Agency**.

1. Dementia as a Priority in Health and Aged Care

Issue

Dementia has a major impact on all aspects of the Australian health and aged care system. Due to the termination of the Dementia Initiative in the last budget, as of 2013 there will no longer be the capacity to plan and coordinate action to combat the dementia epidemic as a health priority across the health and aged care systems. Dementia will no longer be a national health priority.

The Productivity Commission in its final report *Caring for Older Australians* recommends changes to the aged care system to create a more flexible and sustainable system which will benefit older people including those people with dementia. The recommendations in the report did not recognise that dementia must be centre stage in the reform of aged care.

Current situation

There is no longer room for any doubt about the economic and social impact of dementia in Australia on the health care system:

- An estimated 269,000¹ Australians currently live with dementia
- Without a major medical breakthrough, this number is expected to soar to about 981,000 by 2050¹
- Each week, there are 1,500 new cases of dementia in Australia. That is expected to grow to 7,400 new cases each week by 2050²
- There are approximately 16,000¹ people in Australia with Younger Onset Dementia
- Dementia is the third leading cause of death in Australia, after heart disease and stroke³
- One in four people over the age of 85 have dementia¹
- An estimated 1.2 million Australians are caring for someone with dementia⁴
- Dementia has an impact on every part of the health and aged care system
- The total estimated worldwide costs of dementia were US\$604 billion in 2010⁵
- These costs account for about 1% of the world's gross domestic product
- If dementia were a country, it would be the world's 18th largest economy⁵
- If it were a company, it would be the world's largest, exceeding Wal-Mart (US\$414 billion) and Exxon Mobil (US\$311 billion)⁵
- Australia faces a shortage of more than 150,000 paid and unpaid carers for people with dementia by 2029⁶
- The cost of replacing all family carers with paid carers is estimated at \$5.5 billion per annum⁶

- 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 GDP²
- 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 spending²
- Dementia is already the single greatest cause of disability in older Australians (aged 65 years or older)²
- More than 50% of residents in Australian Government-subsidised aged care facilities have dementia (104,400 out of 198,500 permanent residents in 2008-09).⁷

Alzheimer's Australia agrees with the architecture for reform set out in the Productivity Commission report and particularly the elements that include providing greater consumer direction, assistance for carers, being easier to navigate and providing greater community care options through the separation of care and accommodation. The reforms will benefit individuals with dementia, but the reforms will only be successful if underpinned by a comprehensive strategy to address dementia.

The majority of residents in aged care have dementia, it is the most disabling of all conditions among older people and is one of the main causes of institutionalisation. Dementia complicates the management of other health conditions such as diabetes and heart attacks^{8,9}. Many individuals with dementia live in the community and many receive no formal support or care. This is in part due to the lack of appropriate services. The rapidly ageing Australian population means that reform needs to happen soon before we are faced with the prospect of trying to provide care for the increasing number of older Australians over the next 20 years in an unsustainable system.

The Government has committed to action on aged care reform in this term of Government. The Minister for Health and Ageing has already started a 'listening tour' in which he is consulting with older Australians about the implications of the Productivity Commission and wider questions on ageing.

Outcome

A coordinated approach to addressing dementia that recognises the impact of dementia on the aged care and the broader health care system.

The Governments response to the Productivity Commission should include:

- A recognition of dementia as core business of aged care
- A funding model which takes into account the extra costs of providing quality care to individuals with dementia
- A plan for providing dementia training to both aged care workers and individuals involved in the new gateway assessment system

- A plan to ensure integration between the aged care and mental health system to meet the needs of individuals with behavioural and psychological symptoms of dementia.
- The coordination of the aged care reform process with disabilities to ensure that individuals with younger onset dementia have access to an integrated system of care

The elements of the Dementia Action Plan recommended in the following sections would:

- Support the implementation of the aged care reforms by strengthening the infrastructure to improve quality care through training, the better management of the Behavioural Psychological Symptoms of Dementia, the improvement of care practices through knowledge translation and research.
- Improve the quality of life of people with dementia and their family carers by addressing key issues of concern to consumers in health care that impact on aged care – the timely diagnosis of dementia, safer hospitals for people with dementia, and support and counselling for families. Address not only the care of people with dementia now but begin to reducing the future number of people with dementia.

Action

The Government should act to implement aged care reform in the 2012/2013 budget and to ensure it has a focus on dementia. The Government should also implement a Dementia Action Plan to address the impact of dementia across the health care and aged care sectors.

2. Awareness

Issue

Many Australians know very little about what dementia is or how it develops. This lack of awareness means that some people may not seek help when they experience symptoms of dementia. There is confusion around the disease which can lead to fear and stigma.

Current situation

- Australians associate dementia with loss of memory and difficulties with daily functions, but most are unaware of the effect of dementia on language or mood.¹⁰
- Dementia is the third leading cause of death in Australia, yet most Australians are not aware that it is a terminal illness.⁸
- Two out of three Australians are scared of developing dementia - a fear second only to the fear of developing cancer.⁸
- 56% of carers report that people with dementia are discriminated against.⁸
- Almost a third of Australians say that they would feel uncomfortable spending time with someone with dementia.⁸
- Individuals who believe that dementia is associated with stigma are less likely to seek help if they begin to experience memory or other cognitive changes.¹¹
- In a recent pilot survey about stigma and dementia:⁹
 - 34% of respondents found people with dementia to be irritating;
 - 11% said they would avoid spending time with people who had dementia; and
 - If diagnosed with dementia, 60% anticipated that they would experience feelings of shame.

Outcome

Reduce the stigma and social isolation that result from dementia. This would mean that:

- Australians would not avoid spending time with people who had dementia and would not anticipate feeling shame if diagnosed with dementia.
- All Australians would know the symptoms of dementia, including symptoms other than memory problems and where to seek assistance if they experience symptoms.
- The community would be aware of the Government's comprehensive strategy to address dementia.

Action

A two year, \$15 million information campaign to tackle community ignorance of dementia. This funding could be sourced from the **Chronic Disease Prevention and Service Improvement Fund** which currently includes some community awareness programs. This campaign would include social marketing, national advertising, community engagement, and education activities to raise awareness about dementia.

3. Diagnosis

Issue

Between 50-80% of people with early stages of dementia are not being diagnosed in primary care.¹² For those who are diagnosed, many do not receive a diagnosis until three years after they first notice symptoms. Timely diagnosis is important as it enables better management of the disease and allows families to access support and plan for the future.

Current Situation

- 94% of Australians say that if they were worried about their memories they would see their GP.¹³
- In Australia it takes an average of 3.1 years from first noticing symptoms to receiving a firm diagnosis of dementia.¹⁴
- GPs often do not complete a full assessment as suggested in the guidelines.¹⁵
- Early symptoms of younger onset dementia are often misdiagnosed as depression or anxiety.
- According to the most recent World Alzheimer's Report, earlier diagnosis could yield net savings of up to US\$10,000 per patient in high-income countries¹⁶
- There are a number of barriers to early diagnosis in primary care and these include:^{17, 11}
 - A belief that there is no benefit to timely diagnosis;
 - Difficulties in differentiating normal ageing from dementia;
 - GPs lack of confidence or knowledge and risk of misdiagnosis;
 - A lack of appropriate specialist diagnostic services, especially in rural areas;
 - Limited time and lack of an effective time-efficient screening tool;
 - Perception that the patient cannot comprehend/cope with the diagnosis; and
 - Fear of damaging the doctor-patient relationship.

Outcome

We want to achieve a reduction in average time between the first appearance of symptoms and the diagnosis of dementia from 3.1 years to 12 months. There is a need for a coordinated approach which brings together stakeholders and consumers to discuss potential strategies, to develop training programs, as well as working through the new Medicare locals to ensure that dementia becomes part of the reporting framework.

Action

Investment of \$53 million over five years to address barriers to timely diagnosis by employing specialist dementia nurses and providing training and education programs for doctors and practice nurses. Funding for this approach could be included in the **Practice Incentives for**

General Practices Fund or the Health Workforce Fund. This should be supported by two additional actions:

- Bring the Department of Health and Ageing together with medical and consumer stakeholders to determine strategies to achieve timely diagnosis.
- Link diagnosis and management of dementia into the current health reform process by acting on the strategies identified through the reform of Primary Care and mandating that Medicare Locals include diagnosis and management of dementia as part of their reporting framework and needs assessment.

4. Care

There is an urgent need to improve the quality of dementia care and ensure sustainable support and care services for all individuals with dementia. This requires a broad range of investment including the National Dementia Support Program, Dementia Behavioural Advisory Services, Acute Care, Knowledge Translation, Training, and services for Younger Onset Dementia and individuals with psycho-geriatric needs.

a) National Dementia Support Program

Issue

The funding for the National Dementia Support Program which provides support to people with dementia and their family carers has not increased in line with the increased demand for services. Even more concerning is that funding for this program is no longer protected in the forward estimates after 2013.

Current situation

The National Dementia Support Program (NDSP) provides support to over 120,000 people with dementia and their family carers each year. NDSP provides world class information resources, skilled dementia counselling, support groups, education and training for both carers and care workers, early intervention strategies such as the Living With Memory Loss programs, and centre-based and outreach support programs.

Evaluations of the National Dementia Support Program (and its predecessor programs) have shown it to be highly valued by consumers and stakeholders and a cost effective way to provide support and to reduce stress for both the person with dementia and their carer.¹⁸

The NDSP funding agreement for 2010-2013 did not increase funding for core services to reflect the increasing numbers of people with dementia. Over this period the projected increase in number of people with dementia will be 14%. It is unreasonable to expect that Alzheimer's Australia can continue to provide the same level of services to a much larger population without increased funding. Between 2012 and 2017 it is estimated that dementia prevalence will increase by 22%.¹

The program currently is not adequately resourced to reach out to regional, rural and Indigenous communities and does not provide any support for new innovative programs. For example, due to limited resources, Alzheimer's NT is restricted to providing services to Darwin and Alice Springs with the occasional outreach visit to Tennant Creek and Katherine. This means that the large number of individuals with dementia outside of these centres are unable to access the support services they require. Other states face similar challenges in reaching out to their regional and remote communities.

Increased funding for NDSP would enable Alzheimer's Australia to ensure its information materials are comprehensive and reflect the most recent research evidence. The Alzheimer's Australia Dementia Help Sheets cover 75 topics and in 2010-11 432,289 Dementia Help Sheets were distributed nationally, plus 53,203 in community languages. The Help Sheets, while being monitored continuously for content accuracy, have not been reviewed as an 'information set' for 7 years. For example, there are currently no information on environmental design issues, Mild Cognitive Impairment, neuroimaging advances, developments in palliative care and dementia and other topics.

The NDSP grant should also provide seed funding to support innovation and respond to changing needs. For example, NDSP could provide funding for a trial of key dementia support workers, similar to the dementia admiral nurses in the UK, which support individuals with dementia throughout their dementia journey, particularly for individuals who do not have family carers.

Other innovative programs could include:

- An ambassador program to provide dementia information to CALD communities
- An online test to detect cognitive changes and encourage people to talk about their memory function
- An expansion of the Memory Lane Cafe program that has been successful in Victoria
- Specialist diagnostic memory clinics modelled after the Cognitive Dementia and Memory Service which was developed by the Victorian Government
- A Mobile Respite Response Team which provides a flexible service to respond with education and support for the family carer and the person with dementia in their own home
- Project to provide greater information and access to emergency respite in crisis situations
- Funding for 'dementia' specialists in Medicare Locals and to work with aged care assessment staff to develop dementia sensitive services
- Enhanced services for younger onset dementia including case managers, counselling for younger family members, and new models of respite.

Encouraging innovation and trialling new programs is key to responding to the rapidly increasing demand for dementia services. Supports for carers have been shown to help people with dementia stay at home longer and reduce the psychological impacts on the carer. Research suggests that programs that involve both the people with dementia and their families, that are more intensive and modified to meet the individual's needs are the most successful in reducing care giver burden and to increase the time that the person with dementia is cared for in the community.¹⁹

If the Government wants to provide people with choices about where they receive care in later life, this must be accompanied by the appropriate supports for both the individual

with dementia and their family member. Without real investment in the National Dementia Support Program it will be impossible for many to continue to care for individuals with dementia at home.

Outcome

Information, counselling and education services that are comprehensive, well resourced and able to meet the increasing demands of greater numbers of individuals with dementia. The growth funding proposed reflects the anticipated growth in the numbers of people with dementia, the continuation of the \$2 million one off funding for special services access officers working with CALD and Indigenous communities and with gay and lesbian groups as well as funding to broaden the reach of NDSP and provide seed funding for new innovative programs.

Action

Investment of an additional \$22 million in the National Dementia Support program to respond to increased demand in services, to provide better support services for individuals in regional and remote areas and to create innovative services which address the changing needs of individuals with dementia and their carers. This program could be funded under a single five year agreement through the **Aged Care Improvement and Healthy Ageing Grant Fund**, **Single Point of Contact for Health Information, Advice and Counselling Fund**, **the Aboriginal and Torres Strait Islander Chronic Disease Fund** and **the Rural Health Outreach Fund**.

b) Dementia Behavioural Management Advisory Services

Issue

DBMAS provides much needed clinical advice and support to carers and to community and residential service providers on the management of Behavioural and Psychological Symptoms of Dementia (BPSD). These services are under resourced and not adequately promoted.

Current situation

DBMAS combines 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 alongside those provided under the National Dementia Support Program.

The Dementia Behaviour Management Advisory Services have been shown to be effective in increasing the capacity of residential care staff to provide dementia care in

terms of both increasing confidence and skills. Staff believe that this has led to an improvement in quality of life for some people who experience behavioural and psychological symptoms of dementia.

With increasing numbers of individuals with dementia and an increased focus on community care there will be greater need for DBMAS services going into the future. These services are important both in supporting individuals with dementia but also in providing important resources to carers and staff. DBMAS services can also assist carers in terms of increasing their skills in responding to these behaviours and may enable carers to keep a person with dementia at home for longer.

Outcome

High quality support and training for care staff and informal carers to assist them in caring for individuals with behavioural and psychological symptoms of dementia. This may enable individuals with dementia to be cared for in the community for a longer period of time.

Action

Investment of an additional \$30 million in the Dementia Behavioural Advisory Services over the next five years to assist informal and formal carers to better manage the Behavioural and Psychological Symptoms of Dementia. The funding for this program would come from the **Aged Care Improvement and Healthy Ageing Grant Fund**.

c) Acute Care

Issue

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

Current situation

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.²⁰ Many of these individuals may not be identified as having dementia and therefore do not receive appropriate care.²¹ In some cases this may lead to an extended length of stay and a preventable admission to a residential facility.

Even for people who are recognised as having dementia, hospitals can be dangerous places. Often the specific needs of individuals with dementia are not addressed.²² Individuals with dementia stay longer in hospitals than patients without dementia, even after accounting for their principal reason for admission and procedure received.²³

There are also a number of negative outcomes associated with long stays in hospitals for people with dementia including polypharmacy, nutrition deficiencies, skin tears, pressure areas, fall-related injuries, and confusion due to multiple bed and hospital transfers.²⁴

Studies from the UK suggest that at any one time, up to 70% of patients with dementia in hospital may be more appropriately treated in alternative settings and that lengths of stay for patients with dementia could be reduced by providing appropriate services in the community.²⁵ These changes also have the potential to lead to substantial hospital cost savings.²⁶

Outcome

Better outcomes for individuals with dementia in the hospital system including reduced falls, shorter stays, and appropriate care and identification. These outcomes will also lead to savings to the hospital system through reduction in complications and number of days spent in hospital.

Action

Develop systems to make hospitals safer places for people with dementia by increasing recognition of those with dementia and improving coordination and support systems. An investment of \$41million over five years could be funded through the **Health System Capacity Development Fund**.

d) Knowledge Translation

Issue

The uptake of research evidence is generally inadequately carried through in medical practice, care and policy. In order for Australia to provide the best quality care for individuals with dementia we need to ensure we make use of the investment in research to improve the quality of care.

Current situation

There is currently a huge gap between what is known about dementia and dementia care from the research evidence and what type of care and management of dementia is provided in practice. This is not unique to dementia. Evidence suggests that 86% of biomedical research never makes it into practice. Without systematic efforts to bridge the gap between evidence and practice and it can take up to 17 years for basic medical research to result in practice change. Much of the health care that is provided is inconsistent with the research evidence.

Alzheimer's Australia has established the National Quality Dementia Care Initiative to address this gap between the research evidence and current practice. This Initiative is unique in that it is consumer driven with the Consumer Dementia Research Network determining priorities for knowledge translation projects and making final funding decisions. The Initiative funds national projects which aim to improve the quality of dementia care through getting research into practice. This Initiative has received \$3 million in funding from the J.R. and J.O Wicking Trust and Bupa Care. This funding will only sustain the work of the Initiative until 2013.

This program builds on infrastructure established by Government by involving partners from the National Dementia Support Program, the Dementia Collaborative Research Centres, and the Dementia Training Study Centres.

The two projects that have received funding through this program include:

- **The Dementia Enabling Environments Project** which will provide guidelines for the creation of dementia friendly environments, including recommendations for the design of aged care homes. This project, proposed by Alzheimer's Australia WA, will engage architects, designers, aged care organisations and members of the community to optimise built environments for people with dementia.
and
- **Personalised-Care Management Strategies** based upon the Montessori model. This initiative is designed to reduce agitation and promote engagement among aged care residents. Led by Professor Daniel O'Conner from Monash University, this project will teach family carers new ways to interact with their relative once they enter a nursing home.

Each project will receive \$250,000 in funding

This Initiative has the potential to lead to real improvements in the quality of dementia care in Australia based on the investment Government has already made in dementia research. The small investment required to continue funding for this program will have the potential for significant returns. Without specific funding for knowledge translation, the investment in dementia research in Australia will not lead to changes in practice.

Outcome

High quality, evidenced-based dementia care and the transformation of the years of investment in dementia research by Government into real improvements in quality of care and support for individuals with dementia.

Action

The Commonwealth should build on the existing National Quality Dementia Care Initiative to promote the rapid uptake of research into practice in order to support high quality evidence based dementia care \$1 million per annum for project funding. This program could be funded through the **Health System Capacity Development Fund and/or Aged Care Service Improvement and Healthy Ageing Grants Fund**.

e) Training and Professional Development

Issue

To achieve high quality dementia care there is a need for a service environment that supports the adoption of best care practices, works in a partnership approach and provides training and education for staff.

Current Situation

Education and training has been found to be an important factor in improving the quality of care in residential care. For example, training and support for aged care staff has been found to be effective in reducing the proportion of residents with dementia who are prescribed psychotropic medications.²⁷

Important progress has been made in expanding education and training opportunities in Australia through the Dementia Initiative, including Dementia Care Essentials and Dementia Training Study Centres (DTSCs). An evaluation of the Dementia Initiative found the DTSCs to be effective, providing high quality training and to provide value for money. The DTSCs and the Dementia Care Essentials are important resources for staff working in community and residential care. Funding for the Dementia Study Training Centres is not guaranteed after the end of 2013 due to the decision in the 2011/2012 health portfolio budget statement.

But more remains to be done to establish pathways for dementia specialists. A recent project that undertook a stock take of dementia curricula and training in Australia found that there is a lack of clear pathways between various programs or course levels and a lack of designated career pathways in the field.²⁸

There is a need for increased training and professional development opportunities for care staff as well as individuals involved in assessment such as Aged Care Assessment Teams or the future staff of the Gateway. The Alzheimer's Australia educators recently reviewed the gaps in the dementia education and development of the aged care workforce. They have identified a number of critical elements which require investment in order to improve care and outcomes for people with dementia. This includes:

- Further investment in foundational dementia education for the entire aged care workforce
- Specialist dementia education that addresses specific topic areas (e.g. Dementia and palliative care, dementia friendly environments, person centred care)
- Rehabilitative therapies dementia qualification

- Need for a subsidy scheme to increase uptake of the complete dementia qualification – Certificate IV in Dementia Practice
- Development of a leadership and mentoring education program to promote organisational change. This program could be used to train a staff member to be the ‘dementia champion’ in an organisation.
- Investment for further development and updating of dementia education programs to ensure that the programs are informed by the latest evidence

Outcome

Care staff and management that are have a good understanding of dementia and best practice dementia care.

Action

Sustainable funding for the Dementia Training Studies Centres and the Dementia Care Essentials and bridging the gap in dementia training programs by increasing funding by \$20 million over five years. This program could be funded through the **Aged Care Workforce Fund**.

f) Services for Younger Onset Dementia

Issue

Individuals with younger onset dementia and those with severe behavioural and psychological symptoms of dementia (BPSD) often find difficulty in getting access to appropriate services.

Current Situation

Individuals with Younger Onset Dementia

- In 2011 there are approximately 16,000 individuals who have younger onset dementia.¹
- There is a significant risk of younger people with dementia being shifted between disability and aged care services. When disability services are no longer able to meet a younger person’s needs due to the progression of dementia, the person and their family carers are required to navigate a second unfamiliar system.
- Carer burden is significantly higher among carers of individuals with younger onset dementia.²⁹
- There is a lack of appropriate aged care facilities and respite services for individuals with younger onset dementia.

Outcome

Access to seamless services regardless of the individuals age.

Action

Investment to develop appropriate services for people with younger onset dementia. This could be funded through the **Aged Care Service Improvement and Healthy Ageing Grants Fund**.

g) Services for Individuals with Severe BPSD

Issue

Individuals with severe behavioural and psychological symptoms of dementia (BPSD) often find difficulty in getting access to appropriate services.

Current Situation

Individuals with severe BPSD

- Care for individuals with **severe** BPSD and/or co-morbid psychiatric disorders is challenging and requires coordination of aged care and mental health services.
- It is estimated that approximately 10% of individuals with dementia have severe BPSD, which equates to approximately 26,000 individuals in 2011. These individuals have complex care needs that can not always be addressed within a typical aged care setting.
- Individuals with severe BPSD often face problems with access to appropriate care because of structural barriers between the state-funded mental health system and the Commonwealth funded aged care systems.
- The Aged Care Funding Instrument (ACFI) provides a behavioural supplement but this supplement does not cover the true costs of providing care for those with severe behavioural concerns.

Outcome

Access to seamless services that meet the needs of individuals with severe BPSD.

Action

Investment to develop appropriate services for people with severe behavioural and psychological symptoms of dementia. This could be funded through the **Aged Care Service Improvement and Healthy Ageing Grants Fund**.

5. Research

Issue

Understanding the causes of dementia and finding cures or ways to delay its progression will remain beyond reach without much greater investment in research.

Current Situation

- By 2030 there will be 565,000 people with dementia.¹
- Dementia will become the third greatest source of health and residential aged care spending within two decades.²
- If the onset of Alzheimer's disease could be delayed by five years, the numbers of people with dementia would be halved (between 2000 and 2040).³⁰
- Dementia research is grossly underfunded in relation to health and care costs, disability burden and prevalence compared to other chronic diseases.³¹
- In the 2010-11 financial year, National Health and Medical Research Council research funding was \$144 million for cancer, \$97.4 million for research on cardiovascular disease, \$63.1 million for diabetes. Alzheimer's disease and other types of dementias received only \$19.3 million.³²
- Australia has some of the best dementia researchers in the world. These scientists have begun to respond to the challenge of dementia by forging ahead with innovative and world-leading breakthroughs in areas such as neuroimaging, stem cell therapies, neurogenesis and biomarkers.
- New treatments to cure, prevent or delay dementia can only come from rigorous scientific research. Such research relies both on attracting and retaining the best and brightest scientists to the field, and on long-term investment in research programs from the government.
- Australia has the scientific skills and capacity to fight dementia we just need the Federal Government to invest.

Outcome

Reduce the future number of people with dementia

Action

An additional \$40 million investment per year into dementia research through the National Health and Medical Research Council (NHMRC). This would be equivalent to a total research spend of about 1% of the total cost of dementia care.

6. Risk Reduction

Issue

There are ways of reducing the risk of dementia through lifestyle changes and vascular risk factor management but most Australians are unaware of this.

Current Situation

- There is now good evidence that we can reduce our risk of dementia by taking control of alcohol use, blood pressure, body weight, cholesterol, depression, diabetes, diet, head injury, mental activity, physical activity, smoking and social activity.
- Only 50% of Australians believe that it is possible to reduce the risk of developing Alzheimer's disease and other forms of dementia.⁸
- Even among those who are aware there is something they can do to reduce risk, most are only aware of the benefits of staying mentally active.⁸
- There is very little understanding of the links between physical and mental health. For example, approximately 80% of Australians are not aware of the potential benefits of reducing high blood pressure, cholesterol and avoiding head injuries.⁸
- It has been estimated that half of all cases of Alzheimer's disease (the most common form of dementia) could be attributed to modifiable risk factors.³³
- It is also estimated that significant numbers of dementia cases could be prevented by addressing risk factors. For example, around 100,000 fewer Australians would have dementia in 2050 if physical inactivity rates were reduced by 5% every 5 years.³⁴
- The modifiable risk factors for dementia overlap with many other chronic diseases such as heart disease and diabetes.
- Some chronic diseases such as diabetes are themselves risk factors for dementia.
- Alzheimer's Australia has developed and successfully implemented the first stage of the Mind Your Mind® public education program which provides information on ways to reduce risk for dementia.

Outcome

Reduce the risk of dementia for Australians

Action

Funding for a \$4 million public education campaign to make Australians aware that they may be able to reduce their risk of dementia both by management of other chronic diseases which increase the risk of dementia (e.g. stroke, diabetes, obesity) and by changes in lifestyle including social and mental activity, nutrition and physical exercise. This program could be supported through the **Health System Capacity Development Fund** which already supports a number of preventive health programs or it could be funded through the National Preventive Health Agency.

Appendix A

Additional Funding 2012/13 to 2016/17

Area of Funding	\$ million					
	2012/13	2013/14	2014/15	2015/16	2016/17	Total
Awareness	5	10	0	0	0	15
Diagnosis	0	8	15	15	15	53
NDSP	3	4	5	5	5	22
DBMAS	2	4	6	8	10	30
Acute Care	1	10	10	10	10	41
Knowledge Translation	1	1	1	1	1	5
Training	0	2	4	6	8	20
Psychogeriatrics & Younger Onset Dementia	4	14	24	29	39	110
Research	40	40	40	40	40	200
Risk Reduction	2	2	0	0	0	4
Total	58	95	105	114	128	500

This funding is additional to current funding for these programs on the basis that the Government indicated that the introduction of flexible funding in place of the Dementia Initiative was not a savings measure.

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- ¹ Caring Places: Planning for Aged Care and Dementia 2010 – 2050, Access Economics, July 2010
- ² Keeping Dementia Front of Mind: Incidence and prevalence 2009 – 2050, Access Economics, 2009
- ³ Causes of Death, Australia, 2009, Australian Bureau of Statistics, May 2011
- ⁴ Pfizer Health Report Issue #45 – Dementia, March 2011
- ⁵ World Alzheimer Report 2010, The Global Economic Impact of Dementia, ADI 21 September 2010
- ⁶ Making Choices, Future Dementia Care: Projections, Problems and Preferences, Access Economics, May 2009
- ⁷ Dementia among aged care residents: first information from the Aged Care Funding Instrument, Australian Institute of Health and Welfare, May 2011
- ⁸ Sloan, Trogan, Curtis, Schulman 2004. The Effect of Dementia on Outcomes and Process of Care for Medicare Beneficiaries Admitted with Acute Myocardial Infarction.
- ⁹ Sloan & Taylor. 2002. Effect of Alzheimer Disease on the Cost of Treating Other Diseases
- ¹⁰ Pfizer Health Report Issue #45 – Dementia, March 2011
- ¹¹ Unpublished report. University of Wollongong
- ¹⁰ Market research conducted for Alzheimer's Australia by Newspoll Sept.2004
- ¹² World Alzheimer's Report 2011 The Benefits of Early Diagnosis and Intervention, ADI September 2011.
- ¹³ Market research conducted for Alzheimer's Australia by Newspoll Sept.2004
- ¹⁴ Alzheimer's Australia, Paper Number 24- Timely Diagnosis of Dementia: Can we Do Better?
- ¹⁵ Williams J., Byrne J., Pond, D (2006). DCRC Summary: Dementia Identification, Assessment and Management in Community- Based Primary Health Care: A review of the international literature 1995-2006.
- ¹⁶ Alzheimer's Disease International .World Alzheimer's Report 2011.
- ¹⁷ Brodaty (2005). DCRC: Six Reasons Why Early Diagnosis of Dementia Does Not Occur and Ten Reasons Why It Is Important
- ¹⁸ Dementia Initiative- National Evaluation 2009.
[http://www.health.gov.au/internet/main/publishing.nsf/Content/500DD5C951D7E214CA2578170017A8F9/\\$File/LAMAOverview.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/500DD5C951D7E214CA2578170017A8F9/$File/LAMAOverview.pdf)
- ¹⁹ Brodaty, Green & Koschera (2003). Meta-analysis of Psychosocial Interventions for Caregivers of People with Dementia.
- ²⁰ Hill K, Vu M & Walsh W 2007. Falls in the acute hospital setting - impact on resource utilisation. Australian Health Review 31:471-7.
- ²¹ Maslow & Mezey (2008) Hill K, Vu M & Walsh W 2007. Falls in the acute hospital setting - impact on resource utilisation. Australian Health Review 31:471-7.
- ²² Kurrle SE 2006. Improving acute care services for older people. Medical Journal of Australia 154:427-8.
- ²³ Alzheimer's Society 2009. Counting the cost: Caring for people with dementia on hospital wards. Great Britain: Alzheimer's Society.
- ²⁴ Foreman P & Gardner I 2005. Evaluation of education and training of staff in dementia care and management in acute setting. Report for the Department of Human Services.
- ²⁵ Balance of Care Group in association with the National Audit Office 2006. Identifying alternatives to hospitals for people with dementia: Report of findings.
- ²⁶ Report by the Comptroller and Auditor General 2007. Improving services and support for people with dementia HC 604 Session 2006-07. London: National Audit Office.
- ²⁷ Prasad (2008) Report by the Comptroller and Auditor General 2007. Improving services and support for people with dementia HC 604 Session 2006-07. London: National Audit Office.
- ²⁸ Doyle (2009) International perspectives on Dementia Education, Training and Knowledge Transfer.
- ²⁹ Freyne, Kidd, Coen & Lawlor, (1999) Burden in carers of dementia patients.
- ³⁰ Access Economics (2004) Delaying the Onset of Alzheimer's Disease: Projections and issues, Report for Alzheimer's Australia, Canberra, September.
- ³¹ Alzheimer's Australia, Paper Number 16 – Australian Dementia Research: Current Status, Future Directions?, 2008
- ³² NHMRC: Research funding statistics and data: Accessed 1 June 2011:
<http://www.nhmrc.gov.au/grants/research-funding-statistics-and-data>

³³ Barnes & Yaffe (2011). The projected effect of risk factor reduction on Alzheimer's disease.

³⁴ Binod, Brown & Ranmuthugala. (2010). Modelling the impact of modifying lifestyle risk factors on dementia prevalence in Australian population aged 45 year and over, 2006-2051