

BUDGET SUBMISSION 2011

Executive Summary

The extent and impact of the dementia epidemic are now well established:

- There are over 250,000 Australians with dementia.
- The number of Australians with dementia will double to 565,000 by 2030 and nearly double again to about 1 million in 2050.¹
- The cost of replacing all family carers with paid carers is estimated at \$5.5 billion per annum.²
- Australia faces a shortage of more than 150,000 carers by 2030.³
- The cost of dementia care in 2008 is estimated at \$5.4 billion per annum.⁴
- 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.⁵
- By the 2060's 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.⁶
- Dementia is already the largest single cause of disability in older Australians (aged 65 years or older) and is responsible for one year in any six of years of disability burden for this group.⁷
- Dementia is the third most common cause of death after heart disease and stroke.⁸
- The risk of dementia may be reduced by lifestyle and health behaviours, but 49% of Australians do not know.⁹

A National Plan is needed to combat dementia to:

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

The Plan should ensure that people with dementia of all ages benefit from the Gillard Government's comprehensive reform agenda for health and hospitals, primary care, aged care, mental health and disabilities. Action should be coordinated through the Dementia Initiative to ensure that linkages are made across different policy and service areas.

In the 2011 budget, Alzheimer's Australia is seeking:

- **A long term commitment to the staged implementation of the reform of aged care.**
- **Immediate action through additional funding for the Dementia Initiative of \$178.9 million over 3 years. Funding details are set out at Attachment A**

This submission sets out details of the immediate action required to address gaps and priorities in the Dementia Initiative in response to the LAMA evaluation.

The Dementia Initiative – Making Dementia a National Health Priority

An immediate funding increase is necessary to respond to the increasing numbers of people with dementia (14% increase 2010-2013) and gaps in the current Initiative.

The proposals included in the attached submission are to:

- 1) **Improve health care** for people with dementia through timely diagnosis of dementia and making acute care safer for people with dementia.
- 2) **Reduce the future numbers of people with dementia** through increased investment in research into the cause and prevention of dementia and in risk reduction programs.
- 3) **Promote quality dementia care** through dementia specific qualifications, expanded Dementia Behaviour Management Advisory Services and knowledge translation and coordination.
- 4) **Increase support for people living with dementia** through the National Dementia Support Program.
- 5) Provide services for people with **younger onset dementia**.

The case for action in respect of each of these is attached.

The Gillard Reform Agenda

The 2011 Budget should contain a long term commitment to the staged implementation of the reform of aged care. Alzheimer's Australia will seek priority in those staged reform processes for:

- Increased choice and flexibility in service provision for older people and people with dementia.
- Expanded access to quality dementia community and residential care services with an increased priority for community care (particularly respite).
- Measures to ensure increased equity in access to services for all Australians no matter where they live or their ethnicity.

As part of those staged implementation reforms the government should set up a stakeholder group comprising consumer organisations, service providers, professional and staff organisations to be a sounding board for the development of detailed proposals which arise in response to the Productivity Commission's work.

The **Productivity Commission Disability and Support Inquiry** has significance for younger people with dementia. There is a need to ensure that services for this group are available and adequately funded, either through the aged care system or disability services.

Lastly, the government's commitment to give **priority to mental health** is an opportunity to increase services and provide appropriate care to those with dementia and severe psychiatric issues or depression.

Alzheimer's Australia recommends:

- Action:** Fund a review process involving the major stakeholders in primary care to report to the Minister for Health Ageing on the action needed to achieve timely diagnosis of dementia and ongoing management (\$1 million) and to take appropriate action based on this review to improve diagnosis of dementia across Australia (\$18 million).
- Action:** Federal funding of \$20 million from 2011/12 to 2013/14 to implement a national program of action to improve the care and safety of people with dementia in acute care.
- Action:** Federal funding of \$3 million from 2011/12 to 2013/14 to implement a national program of action to increase awareness of and access to advance care planning and palliative care.
- Action:** An additional investment of \$100 million in dementia research from 2011/12 to 2013/14 through the National Health and Medical Research Council with the objective of establishing a target of 1% of the care costs of dementia in the longer term (about \$50 million per annum).
- Action:** A public education campaign based on Mind Your Mind[®] to be funded at a cost of \$4.6 million from 2011/12 to 2013/14.
- Action:** An additional investment to pilot a new dementia specialist qualification at the Diploma level developed by Alzheimer's Australia (a total of \$2 million in 2011/12 and 2012/13).
- Action:** Fund a review of Dementia Behaviour Advisory Services and the most effective delivery models with a view to increasing the capacity of the DBMAS services in 2011/12 (\$300,000), and to fund increased capacity of DBMAS in Queensland (\$500,000 per year)
- Action:** The Commonwealth to provide funding to the National Quality Dementia Care Initiative in order to promote co-ordination and collaboration across the Dementia Initiative and to improve the uptake of research into practice (\$1million p.a. for project funding and \$300,000 p.a. for administration from 2011/12 to 2013/14).
- 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 \$3.3 million per annum (i.e. to \$12.3 million) in 2011/12 and 2012/13 to respond to the growth in the number of people with dementia of 14 per cent over the term of the current NDSP

and to maintain services established through the off funding (\$2 million) provided in 2010/11.

Increase funding for national awareness activities through NDSP including the roll out of a national school resource kit on dementia to increase awareness (\$1 million pa over 2011/12-2013/14).

Action: Fund pilot projects to demonstrate what models of care may work best for individuals with younger onset dementia (a total of \$15M from 2011/12 to 2013/14).

THE DEMENTIA EPIDEMIC: BUDGET PRIORITIES FOR 2011/12 to 2013/14.

INTRODUCTION

Funding for the Dementia Initiative – Making Dementia a National Health Priority has been continued by the Gillard Government. The evaluation has shown that the funding has been used effectively on the introduction of Extended Aged Care at Home (Dementia) packages, expanded training opportunities, funding for dementia research and support for people living with dementia through the National Dementia Support Program administered by Alzheimer's Australia.

The challenge now is to address new priorities in the Dementia Initiative, to extend the reach of the services provided through the Dementia Initiative and to ensure that the reform agenda of the Gillard Government in health and hospitals, aged care, mental health, and disabilities benefits those with dementia. The Ministerial Dementia Advisory Group should advise the Minister for Ageing on the development of initiatives in related policy and service areas to maximise the benefit of the Government's reform agenda for people with dementia and their family carers.

The twin objectives of a National Plan should 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 set out the elements of a comprehensive plan to combat dementia in ***Dementia: facing the epidemic***. Based on that plan this paper sets out the immediate priorities that need to be addressed in order to achieve the vision of a world class dementia care system.

HEALTH CARE

1) Timely Diagnosis

Research commissioned by Alzheimer's Australia indicates that over 90%¹⁰ 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.¹¹
- The gap between first symptoms and diagnosis for those who do receive a formal diagnosis ranges between 10 and 32 months.¹²
- Up to 90% of mild dementia cases go undetected in general practice.¹³

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 recognised, 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.¹⁴

There are benefits to timely diagnosis including the better management of behavioural change as dementia progresses, prevention of avoidable complications from co morbid illness such as diabetes and enabling improved legal, financial and care planning. Timely diagnosis is also important for family carers, as it allows them to access support that can reduce their health risks and the associated costs for individuals and government.

Given the benefits of timely diagnosis it is important to consider how concerns about delays in diagnosis can be addressed through the Gillard Government's primary health care strategy. Alzheimer's Australia proposes that the first step is to involve stakeholders including the Royal College of General Practitioners, the Australian and New Zealand Society for Geriatric Medicine, the Australian Divisions of General Practice, the AMA, the Royal College of Nursing Australia, Australian Nurses Federation and the Australian Practice Nurses Association. A review should be held in the context of the Australian Government's reform agenda that would:

- Assess the evidence base for concerns about the timely diagnosis and ongoing management of dementia.
- Develop proposals that address the concerns about timely diagnosis.

In the review it would be important to consider options such as:

- Focusing attention on adequate incentives and training for GPs and Practice Nurses to secure an appropriate response to individuals presenting with cognitive impairment.
- Methods to improve the primary care response to the chronic disease elements of dementia such as counselling, access to community based support, medical management of emergent disorders and legal and driving issues.
- The possibility of providing incentives to reduce the time from symptom presentation to diagnosis by establishing a "time to diagnosis" target.

Part of the background for such a meeting would be supplied by the phase one report by Urbis *Dementia in Primary Care* and by the work of Professor Dimity Pond.

Action: Fund a review process involving the major stakeholders in primary care to report to the Minister for Health Ageing on the action needed to achieve timely diagnosis of dementia and ongoing management (\$1 million) and to take appropriate action based on this review to improve diagnosis of dementia across Australia (\$18 million).

2) Acute Care

Acute care remains 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 to provide the additional attention required to provide quality care to a person with dementia, or unaware of how to do so.

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.¹⁵

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 often detrimental to a person with dementia and its impact is felt well after discharge.

While admissions are less commonly made for dementia-related 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.¹⁶

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

- Minimises unnecessary hospital admissions for people with dementia. This can be achieved by encouraging advance 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 a sense of security 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 assessment of cognitive status at admission, improved access to specialist dementia programs and specialist support for people with dementia who have co-morbidities.
- 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 in areas including communication and carer involvement.

There have been a number of small projects implemented through Alzheimer's Australia to improve the quality of dementia care in acute care. For example, Alzheimer's Australia WA has been funded by WA Department of Health to provide professional development training to acute care staff. Alzheimer's Australia has also been involved in a demonstration project of a symbol for cognitive impairment and training for staff, an approach which is recommended

by people living with dementia. Although both of these projects show promise, there is a need for a national coordinated program of action to improve the care for people with dementia in acute care.

Action: Federal funding of \$20 million from 2011/12 to 2013/14 to implement a national program of action to improve the care and safety of people with dementia in acute care.

3) End of Life Care

Many people with dementia experience poor quality care at the end of their lives. Issues can include inadequate pain management, inappropriate hospitalisation or medical intervention, and a lack of timely and appropriate consultation (with the person with dementia or their family carers) over their choices regarding care.¹⁷ Furthermore, there is often a lack of appropriate emotional support and information provided to family and family carers during end-stage dementia.

Advance care planning and palliative care are the preferred methods for ensuring quality end of life care for people with dementia. Individuals in the early stages of dementia should be supported and encouraged to participate in advance care planning to express their views about medical treatment and their preferences about end of life treatment. Families need to be provided with sufficient information after an individual receives a diagnosis of dementia in order to take appropriate steps in advanced care planning.

Many individuals with dementia and their families want palliative care which focuses on relieving symptoms rather than trying to cure or delay the progression of terminal disease. They also want timely and appropriate information regarding the condition, and the opportunity to be involved in medical and care decision making. It is also important that emotional and practical support is provided to people with dementia and family carers. Research suggests that often individuals with dementia are unable to access desired palliative care

Action: Federal funding of \$3 million from 2011/12 to 2013/14 to implement a national program of action to increase awareness of and access to advance care planning and palliative care.

REDUCE THE INCIDENCE AND PREVALENCE OF DEMENTIA

1) Investment in Dementia Research

Investment in dementia research has increased in recent years, in part due to funding through the Dementia Initiative. Nevertheless, in relation to health and care costs, disability burden and prevalence, dementia research is significantly underfunded in comparison to other major chronic diseases. Between 2002 and 2007, dementia research received only half as much funding as cancer as a proportion of the estimated burden of each disease. As a proportion of direct care costs, the extent of this funding shortfall is even more apparent, with

dementia research receiving less than a fifth of the funding allocated to cancer or diabetes. Furthermore, on current trends, the magnitude of the discrepancy is projected to increase, with dementia research funding as a proportion of direct care costs declining to just 5% of the equivalent research funding on cancer and respiratory disease by 2023.¹⁸

The National Health and Medical Research Council currently spend about \$22 million per annum on dementia research. Cancer attracts nearly \$160 million, cardiovascular disease around \$110 million and diabetes over \$60 million.¹⁹

There is a need for increased priority and targeted funding to support 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.
- Identify those most at risk of developing dementia.
- Improve the quality of dementia care.

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 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.
- There is high quality care available for all individuals with dementia and research is quickly put into practice to improve this care.

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.²⁰

Action: An additional investment of \$100 million in dementia research from 2011/12 to 2013/14 through the National Health and Medical Research Council with the objective of establishing a target of 1% of the care costs of dementia in the longer term (about \$50 million per annum).

2) Dementia risk reduction

There is now good evidence to suggest 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 (Early Diagnosis and Prevention) in which Alzheimer's Australia Vic is a partner.

Market research commissioned by Alzheimer's Australia demonstrates that 49% 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 lifestyle factors that may be beneficial. For example, even after prompting, around 40 percent of people did not agree that reducing blood pressure or high cholesterol would help reduce the risk of dementia.²¹

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 people with dementia in the future.

Action: **A public education campaign based on Mind Your Mind® to be funded at a cost of \$4.6 million from 2011/12 to 2013/14.**

MEASURES TO STRENGTHEN QUALITY DEMENTIA CARE

1) Training

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 that can guarantee high quality care. Instead, 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, and training and education for staff.²²

Important progress has been made in expanding education and training opportunities through the Dementia Initiative, including Dementia Care Essentials and Dementia Training Study Centres. But more remains to be done to establish pathways for dementia specialists.

Alzheimer's Australia believes that the immediate priority is to deliver a new 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.

Action: **An additional investment pilot a new dementia specialist qualification at the Diploma level developed by Alzheimer's Australia (a total of \$2 million in 2011/12 and 2012/13).**

2) Dementia Behaviour Management Advisory Services. (DBMAS)

The implementation of these new services has been slow, but they are demonstrating the value of providing 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).

The new services combine 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.

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. There is also a need to increase the funding of services in specific states and territories, particularly those that have dispersed population centres with poor access to specialist services. For example, the Queensland DBMAS estimates that it will need another \$500,000 per year to provide services to Indigenous, rural and remote clients.

Action: Fund a review of Dementia Behaviour Advisory Services and the most effective delivery models with a view to increasing the capacity of the DBMAS services in 2011/12 (\$300,000), and to fund increased capacity of DBMAS in Queensland (\$500,000 per year)

3) Knowledge Translation and Coordination

The Evaluation of the Dementia Initiative indicated a need for greater leadership in integration and collaboration across the Initiative. Alzheimer's Australia believes that rather than taking an administrative approach to this issue, increased coordination could best be achieved through an action oriented model driven largely by consumer priorities.

This action oriented approach could take a number of forms. However, given the scope of activities and organisations supported through the Dementia Initiative, Alzheimer's Australia believes that the ideal model would focus on Knowledge Translation; specifically through the establishment of a number of national-scale collaborative practice improvement projects that bring together the collective knowledge of the various elements of the Dementia Initiative. This approach could maximise opportunities for coordination along with improvements to the services provided through the Initiative by:

- increasing consumer input into dementia research and service delivery;
- promoting greater collaboration and sharing of information between dementia researchers, service providers and consumers;
- improving coordination of action amongst the various elements of the Initiative;
- ensuring that the outcomes of funded research are utilised to maximum effect to the benefit of consumers and service providers;

- ensuring consumer needs and priorities, and the needs and experiences of service providers directly inform and shape the dementia research agenda.

Knowledge Translation is a particularly important priority for the Dementia Initiative as without systematic efforts to bridge the gap between evidence and practice it can take up to 17 years for basic medical research to result in practice change. Alzheimer's Australia believes that a focus on improving practice and care through uptake of research is the best way to facilitate increased coordination and collaboration across the Initiative.

There are a number of ways in which increased coordination through Knowledge Translation could be promoted. In particular, it could be based on the recently established National Quality Dementia Care Initiative (NQDCI) which is administered by Alzheimer's Australia through an initial \$3 million grant provided by the ANZ Wicking Trust and Bupa Care Services. The objective of NQDCI is to improve the quality of dementia care through the rapid dissemination and uptake of research evidence through Knowledge Translation. A nationally representative Consumer Dementia Research Network, funded largely by the three DCRCs has set broad priority areas in which to seek expressions of interest for projects, the first of which will be commissioned early in 2011.

Many of the elements of the Dementia Initiative are already represented within the NQDCI. The NQDCI is overseen by an Executive Committee chaired by Professor Henry Brodaty (DCRC - ABC) and including representatives from each of the three DCRCs, the Consumer Dementia Research Network, the aged care industry (Bupa Care Services), the Federal Department of Health and Ageing and Alzheimer's Australia. With an extended role of enhancing the quality of dementia care through collaboration, this Executive Committee could be expanded to include representatives from the DTSCs and DBMAS so as to engage the major elements of the Dementia Initiative. Importantly, this committee would be very similar in membership and function to the 'Implementation Steering Group' recommended in the evaluation of the Dementia Initiative. The committee could be given an additional and active role in mixing and matching available project funding for knowledge translation to improve the quality of dementia care.

The NQDCI was established in 2009 with funding through to 2012/13, and has already been successful in encouraging increased collaboration amongst key elements of the dementia initiative. As such, Alzheimer's Australia believes that the NQDCI could represent an efficient and cost-effective mechanism of increasing collaboration and coordination within the Dementia Initiative. Minimal additional funding would enable Alzheimer's Australia to expand the committee membership, and to increase funding for Knowledge Translation projects aimed at bringing together dementia researchers, consumers and service providers to develop innovative ways to improve the rigour and the quality of dementia care in Australia through the rapid uptake and utilisation of research.

Action: **The Commonwealth to provide funding to the National Quality Dementia Care Initiative in order to promote co-**

ordination and collaboration across the Dementia Initiative and to improve the uptake of research into practice (\$1 million p.a. for project funding and \$300,000 p.a. for administration from 2011/12 to 2013/14).

4) Support for People Living With Dementia and Awareness

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 the Living With Memory Loss programs, and 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 translation 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.²³

The NDSP has also been assessed as being effective in the provision of carer education by assisting carers, for example, to make better use of respite care and at an earlier stage.²⁴ 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.²⁵

The evaluation of the Dementia Initiative concluded that "the program was operated professionally and compassionately and was highly valued by consumers and stakeholders."²⁶

Significant investment has been made in the NDSP in recent years. The program is well established and supported by consumers.²⁷ As the numbers of people in Australia who have dementia increase, demand for these services will

also rise. It is therefore important that funding for NDSP be linked to the growth in numbers of people with dementia.

A grant was made to Alzheimer's Australia in 2009/2010 that supports critical program infrastructure (e.g. data collection) and special access service officers to promote an understanding of dementia and access to services for those from CALD and Indigenous communities or who are gay or lesbian. This needs to continue until end-June 2013.

Alzheimer's Australia has demonstrated that it made effective use of the funding provided through the NDSP for awareness activities including through Dementia Awareness Week. The advertising dollar equivalent of the media exposure gained is a multiple of 15-20 times the cost of awareness activities.

It is proposed that the current funding of only \$160,000 for awareness activities through the NDSP should be increased to provide for:

- Increased awareness activity at the national level including through Community Service Advertisements and public speaker programs.
- The national roll out of educational materials on dementia for schools across Australia as supported by the Ministerial Dementia Advisory Committee. This resource would be based on the 'Ageing and Changing' school resource kit which has been developed by Alzheimer's Australia Victoria as part of a dementia grants project.

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 \$3.3 million per annum (i.e. to \$12.3 million) in 2011/12 and 2012/13 to respond to the growth in the number of people with dementia of 14 per cent over the term of the current NDSP and to maintain services established through the off funding (\$2 million) provided in 2010/11.**

Increase funding for national awareness activities through NDSP including the roll out of a national school resource kit on dementia to increase awareness (\$1 million pa over 2011/12-2013/14).

5) Younger onset dementia

The lack of recognition of younger onset dementia has meant that the needs of this group have been met through an ongoing reliance on the aged care sector. In 2008, COAG agreed that responsibility for this group should be included under a new National Disability Agreement. Alzheimer's Australia has raised questions with the Minister for Ageing and the Parliamentary Secretary for Disabilities and Children's Services that need to be addressed, including:

- How is the disability sector going to gain an understanding of the care and support needs of people living with dementia?
- What resources are available to develop services appropriate for people with younger onset dementia?

- What requirement is there on jurisdictions to include younger people with dementia within the current initiatives?

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. The progression of dementia in younger people can be quite rapid. The challenge is to develop a smooth and seamless service. One option might be to remove age limits for access to aged care services for those with dementia, and to ensure the services received are appropriate.

Action: Fund pilot projects to demonstrate what models of care may work best for individuals with younger onset dementia (a total of \$15M from 2011/12 to 2013/14).

ATTACHMENT A

Additional Funding 2011/12 to 2013/14

| Area of Funding | \$ million | | | |
|--|-------------|-------------|-------------|--------------|
| | 2011/12 | 2012/13 | 2013/14 | Total |
| Primary Care | 1.0 | 9.0 | 9.0 | 19.0 |
| Acute Care | 5.0 | 7.0 | 8.0 | 20.0 |
| End of Life Care | 1.0 | 1.0 | 1.0 | 3.0 |
| Dementia Research | 20.0 | 30.0 | 50.0 | 100.0 |
| Dementia Risk Reduction | 1.3 | 1.5 | 1.8 | 4.6 |
| Dementia Qualification | 1.0 | 1.0 | - | 2.0 |
| DBMAS | 0.8 | 0.5 | 0.5 | 1.8 |
| Knowledge Translation and Coordination | 1.3 | 1.3 | 1.3 | 3.9 |
| National Dementia Support Program | 3.3 | 3.3 | - | 6.6 |
| Awareness | 1.0 | 1.0 | 1.0 | 3.0 |
| Younger Onset Dementia | 3.0 | 6.0 | 6.0 | 15.0 |
| Total | 38.7 | 61.6 | 78.6 | 178.9 |

Endnotes

- ¹ Access Economics (2010) *Caring Places: Planning for aged care and dementia 2010-2050*, Report for Alzheimer's Australia, July.
- ² Access Economics (2009) *Making Choices: Future Dementia Care: projections, problems and preferences*, A report for Alzheimer's Australia, April.
- ³ Access Economics (2009) *Making Choices: Future Dementia Care: projections, problems and preferences*, A report for Alzheimer's Australia, April.
- ⁴ Access Economics (2009) *Making Choices: Future Dementia Care: projections, problems and preferences*, A report for Alzheimer's Australia, April.
- ⁵ Access Economics (2009) *Front of Mind*, Report for Alzheimer's Australia, August.
- ⁶ Access Economics (2009) *Front of Mind*, Report for Alzheimer's Australia, August.
- ⁷ Access Economics (2009) *Front of Mind*, Report for Alzheimer's Australia, August.
- ⁸ Australian Bureau of Statistics (2009), *Causes of Death Australia.2007*, Cat. No. 3303.0, Canberra, March.
- ⁹ Alzheimer's Australia (2008) Paper 14 – Dementia Risk Reduction: What do Australians Know? Dr Maree Farrow, September
- ¹⁰ Market research conducted for Alzheimer's Australia by Newspoll Sept.2004
- ¹¹ Bond et al. (2005). Inequalities in dementia care across Europe: key findings of the Facing Dementia Survey, *International Journal of Clinical Practice*; 59:s146
- ¹² Bond et al. (2005). Inequalities in dementia care across Europe: key findings of the Facing Dementia Survey, *International Journal of Clinical Practice*; 59:s146
- ¹³ Valcour et al The detection of dementia in the primary care setting, *Arch Intern Med.* 2000 Oct 23;160 (19):2964-8
- ¹⁴ Paterson N E and Pond CD, *The barriers to the early diagnosis of dementia and diagnostic disclosure in primary care*, presented at International Conference on Alzheimer's Disease 11-16 July 2009.
- ¹⁵ Marriott, .J. *The Use of Psycho-tropic Medicines in the Elderly - presentation to Nursing the Confused Elderly Person*, Melbourne 3-4 February 2003 AUSMED Publications.
- ¹⁶ Bynum JPW, Rabins PV, Weller W, Niefeld M, Anderson GF, Wu AW (2004) *The relationship between a dementia diagnosis, chronic illness, Medicare expenditures, and hospital use.* JAGS, 52(2), 187-194.
- ¹⁷ Nuffield Council on Bioethics (2009). *Dementia: Ethical Issues.* October.
- ¹⁸ Brodaty H, Low L-F, Gomez L (2008) *Australian Dementia Research: Current Status, Future Directions?* A report for Alzheimer's Australia, Paper 16, June.
- ¹⁹ NHMRC (2009), Report on the Operations of the NHMRC Strategic Plan 2007-2009 available at <http://www.nhmrc.gov.au/PUBLICATIONS/synopses/ files/NH117.pdf>
- ²⁰ Access Economics (2004) *Delaying the Onset of Alzheimer's Disease: Projections and issues*, Report for Alzheimer's Australia, Canberra, September.
- ²¹ Alzheimer's Australia (2008) *Risk Reduction: What Do Australians Know?* Paper 14, September.
- ²² Alzheimer's Australia (2003) *Quality Dementia Care*, Paper 2, February.
- ²³ Applied Aged Care Solutions (2000) *Dementia Education and Support Program – Telephone Advisory Service and Counselling Program – Evaluation Report*, July.
- ²⁴ Applied Aged Care Solutions (2005) *Evaluation of the Carer Education Training Project – Final Report.*
- ²⁵ Bird M, Cardwell T, Mahler J, Quarter A (2005) *Alzheimer's Australia Early Stage Dementia Support and Respite Project – Final Report on the National Evaluation*, January.
- ²⁶ Dementia Initiative National Evaluation, LAMA Consortium, Overview and Summary, 2009.
- ²⁷ A user survey conducted in 2006 across the range of NDSP services indicated that 90% of respondents (90% counselling, 92% memory centre/ van, 96% education and training, Helpline 95%) said they would recommend the service to a friend in similar circumstances.