



Alzheimer's
Australia
Living with dementia

**NATIONAL HEALTH
AND HOSPITAL
REFORM COMMISSION**

**SUBMISSION FROM
ALZHEIMER'S AUSTRALIA
30TH MAY 2008**

Executive Summary

In 2008, there are an estimated 227,360 people with dementia. By 2030 this figure will have more than doubled to 465,460 and by 2050 this figure will reach 731,030.¹

Dementia needs to be recognised as a major health issue. Older and younger people with dementia and their families and carers use a significant quantity of health services including GPs, hospitals, pharmaceuticals, state mental health services, as well as aged care assessments, community care programs and residential aged care.

Access Economics estimated the direct cost of dementia at over \$3.2 billion in 2002. By the end of this decade, these costs will nearly double. By mid-century, dementia costs may exceed 3% of GDP, from nearly 1% today.²

Dementia is a devastating condition causing progressive neurodegeneration, and is a leading cause of disability burden in Australia. There is currently no cure for dementia but there are preventative strategies for reducing the risk. Despite this, there has been no recognition by health policy makers of the potential for risk reduction. Dementia is linked to other major chronic diseases, in particular cardiovascular disease, obesity, diabetes, Down syndrome and HIV AIDS.³

Fundamental change is necessary to improve the quality of life and health of older people and people with dementia and should comprise:

- 1. Reform of the aged care system with an increased priority in resource allocation in the health and care system to community care in order to strengthen services to family carers and enable older people to stay at home longer. These reforms should:**
 - a) restructure and reform community care so that care is available to respond to a range of needs, without inflexible program boundaries.
 - b) provide choice based on the incorporation of the principle of Consumer Directed Care (CDC) into aged care programs to provide older people and people with dementia and their family carers with the option of taking control over their lives either through cash or individualized budgets managed by service providers.⁴
 - c) consistent with CDC break the link between accommodation and care so that the older person has the choice to combine flexibly different accommodation and care options
- 2. Recognition that dementia is a health issue as well as aged care issue by:**
 - a) increased investment in dementia research;
 - b) the inclusion of dementia in national prevention awareness programs; and,
 - c) taking measures to promote early diagnosis.

IT IS RECOMMENDED THAT:

- 1. Federal funding for community care for people over 65 years should be doubled over 5 years from the 2008-09 estimate of \$2 billion (which is only 24% of the total Commonwealth aged care budget) to \$4 billion.**
- 2. Residential and community programs to be indexed to reflect real cost increases.**

¹ Access Economics "Dementia Estimates and Projections: All States and Territories" (Report for Alzheimer's Australia, 2005) available at <http://www.alzheimers.org.au/upload/EstimatesProjectionsNational.pdf>

² Access Economics "The Dementia Epidemic: Economic impact and positive solutions for Australia" (Report for Alzheimer's Australia, 2003), available at <http://www.alzheimers.org.au/upload/EpidemicFullReportMarch2003.pdf>

³ See, Alzheimer's Australia "Dementia Risk Reduction: The Evidence" (Paper No. 13, Alzheimer's Australia, 2007) available at <http://www.alzheimers.org.au/upload/RiskReductionSept07.pdf>

⁴ See Jane Tilly and Glenn Rees "Consumer Directed Care: A way to empower consumers?" (paper 11, Alzheimer's Australia, 2007) available at <http://www.alzheimers.org.au/upload/CDCEmpowerConsumersTilly.pdf>

3. **Measures be taken to recognize the special needs of people with dementia through:**
 - a) Flexible respite care services embracing the principle of CDC.
 - b) Expansion of Dementia Extended Aged Care at Home Packages.
 - c) Provision for those with psychiatric illnesses or intellectual disabilities as well as dementia.
4. **Increase the funding available to aged care assessment teams so that waiting times for assessment are reduced and that older people have access to advice on planning ahead.**
5. **Investment in dementia research be increased to \$36 million p.a. and maintained at 1.5% of the direct cost of dementia.**
6. **Measures be introduced to achieve early diagnosis, including providing incentives to GPs to upskill and introducing memory clinics on the model of the Cognitive, Dementia and Memory Service (CDAMS) in Victoria. These measures are critical because**
 - a) 18 months or more for a diagnosis of dementia is not acceptable.
 - b) Early diagnosis offers the best opportunity to treat the symptoms of dementia, and allows time for financial and legal planning.⁵
 - c) For younger people with dementia the process of diagnosis can be even more protracted and traumatic.
7. **An awareness program be funded on the basis of Mind your Mind to promote lifestyle changes consistent with reducing the risk of dementia.**
If the average onset of Alzheimer's disease was reduced by 5 years from 2005, then there would be 35% fewer new cases of dementia by 2020, a cumulative saving of \$13.5 billion would be realised.⁶
8. **Measures be taken to improve care for people with dementia in hospitals including:**
 - a) Resourcing for coordinators to assist and train other hospital staff in respect of dementia care.
 - b) Promotion of new approaches to providing hospital care in the home or in residential care to avoid the trauma of moving the person.
9. **Implementation of a symbol for cognitive impairment on the basis of the report funded by the Department of Health from Alzheimer's Australia.**
10. **There is recognition of the needs of special groups:**
 - those with younger onset dementia;
 - People from Indigenous communities; and
 - People from rural and remote parts of Australia
11. **People with dementia should have the same opportunities as all Australians to have a say about their healthcare, now and for the future when they may become unable to express their choices for medical treatment. The current barriers are inconsistent and confusing legislation across Australia, and a lack of community education about advance care planning.**

Alzheimer's Australia supports the proposed principles to guide reform and future directions of the health care system. The approach in this submission is consistent with the principles and, in particular, 1 and 3 (the importance of CDC to choice and sharing), 4 (recognizing the scope for risk reduction in respect of dementia) and 7 (dementia research). The absence of a reference to community care services in Principle 5 is a major omission. Lastly, Principle 8 might refer to legal issues for example in respect of advance care directives.

⁵ See, Alzheimer's Australia "Diagnosing Dementia" (Reference Paper, 2001) available at <http://www.alzheimers.org.au/upload/DiagnosingDementia.pdf>

⁶ Access Economics "Delaying the onset of Alzheimer's Disease: Projections and Issues" (Report for Alzheimer's Australia, 2004) available at <http://www.alzheimers.org.au/upload/DelayingOnsetAccessEconomicsAugust2004.pdf>

SUBMISSION to the HEALTH AND HOSPITALS COMMISSION

Dementia is an issue of increasing importance to the Australian Health and Aged Care system. While dementia is not a normal part of ageing, risk does increase as we age, making dementia a serious, chronic and costly public health problem in light of our ageing population. Dementia is a devastating condition causing progressive neurodegeneration, leading eventually to death. There is currently no cure for dementia, although there are preventative strategies for reducing the risk. Due to its highly disabling nature, dementia is a condition that makes heavy use of health system resources. There is an urgent need for a planned and strategic approach to meet the dementia epidemic across all sectors. The projected financial and societal costs of the dementia epidemic are very high.

- ⇒ In 2008, there are an estimated 227,360 people with dementia. By 2030 this figure will have more than doubled to 465,460 and by 2050 this figure will reach 731,030.⁷
- ⇒ There are currently more than 1000 new cases of dementia each week.⁸
- ⇒ Data from the Australia Institute of Health and Welfare indicate that dementia is the chronic condition projected to show the greatest increase in disease burden by 2023. In 2003 dementia was the 11th largest cause of disease burden in Australia; by 2023 it will be the 4th largest cause.⁹
- ⇒ In 2002 Access Economics estimated the direct and indirect cost of dementia at AUD 6.6 billion.¹⁰ By mid-century, dementia costs may exceed 3% of GDP, from nearly 1% today.¹¹

❖ **Fundamental change is necessary to sustain the quality of life and health of older people and people living with dementia and should comprise reform of the aged care system and recognition of dementia as a health issue.**

1. Reform of the aged care system with an increased priority in resource allocation in the health and aged care system to community care to strengthen services to family carers and enable older people to stay at home longer. These reforms should:

- a) restructure and reform community care so that care is available to respond to a range of needs, without inflexible program boundaries.
- b) provide choice based on the incorporation of the principle of consumer directed care (CDC) into aged care programs to provide older people and people with dementia and their family carers with the option of taking control over their lives either through cash or individualized budgets managed by service providers.¹²
- c) consistent with CDC break the link between accommodation and care so that the older person has the choice to combine flexibly different accommodation and care options.

⁷ Access Economics (2005) "Dementia Estimates and Projections: All States and Territories" Report for Alzheimer's Australia, available at

<http://www.alzheimers.org.au/upload/EstimatesProjectionsNational.pdf>

⁸ Ibid.

⁹ Australian Institute of Health and Welfare, The burden of disease and injury in Australia 2003 (Canberra, Australian Institute of Health and Welfare: 2007)

¹⁰ Access Economics, "The Dementia Epidemic: Economic impact and positive solutions for Australia" (Report for Alzheimer's Australia, 2003), available at

<http://www.alzheimers.org.au/upload/EpidemicFullReportMarch2003.pdf>

¹¹ Access Economics "The Dementia epidemic: Economic impact and positive solutions for Australia" (Report for Alzheimer's Australia, 2003), available at

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¹² See Jane Tilly and Glenn Rees "Consumer Directed Care: A way to empower consumers?" (paper 11, Alzheimer's Australia, 2007) available at

<http://www.alzheimers.org.au/upload/CDCEmpowerConsumersTilly.pdf>

a) Restructure and reform community care so that care is available to respond to a range of needs, without inflexible program boundaries.

Continuity of care is of crucial importance for people with dementia and their families and carers who require consistency and reliability in care provision as their condition deteriorates.

The current system offers little flexibility between program types to support care across the continuum. The most evident gap is between CACP and EACH packages.

The inadequate number of EACH and EACHD packages means that people with dementia may enter residential care prematurely.

b) Provide choice based on the incorporation of the principle of Consumer Directed Care (CDC) into aged care programs to provide older people and people with dementia and their family carers with the option of taking control over their lives either through cash or individualized budgets held by the service provider.

Alzheimer's Australia supports a CDC approach to community care. People with dementia and their family carers should have the option of making their own choices in respect of the care services they need to meet their own individual circumstances. Equally, people who wish to let services make the choice for them should be free to exercise that option.

Arguably, the best way of maintaining a person's independence is to allow them the option to decide what services will enable them to live as independently as possible for as long as possible in the setting of their choosing.

A number of European countries, including the Netherlands and the United Kingdom have introduced this principle in their community care programs. So too have a number of states in the USA. Evaluations of CDC have shown that it provides better outcomes than those that rely on mainstream agency delivered programs.¹³

Consumer Directed Care gives people the option to hire a family friend or neighbour. This could be a valuable option in rural and remote regions of Australia where there are fewer service providers and high costs for staff travel including transport and time to travel long distances. The option would also be likely to be attractive to people from culturally and linguistically diverse backgrounds as they could recruit people from their own communities.

c) Consistent with CDC break the link between accommodation and care so that people with dementia have the choice to combine flexibly different accommodation and care options.

Separate funding streams open the way for the Government to pay a single subsidy for care, with consumers free to choose whether they wish to receive that care at home or in a residential care facility. Currently that choice is seriously limited.

The Aged Care Assessment Team would assess the individual for an appropriate level of care and subsidy. The individual and their family carer would decide, with the Team, where the care would be most appropriately delivered - in a care package in the home or in residential care. For a range of reasons including the health of the carer, residential care may be the best option for some. But for others, remaining in the home or a retirement village may be the preferred option.

¹³ Jane Tilly and Glenn Rees "Consumer-Directed care: A way to empower consumers?" (paper 11, Alzheimer's Australia, 2007) available at <http://www.alzheimers.org.au/upload/CDCEmpowerConsumersTilly.pdf>

2. Recognition that dementia is a health issue as well as aged care issue by:

- a) increased investment in dementia research;
- b) the inclusion of dementia in national prevention awareness programs; and,
- c) taking measures to promote early diagnosis

People with dementia and their families and carers use a significant quantity of health services, including GPs, hospitals, pharmaceuticals, state mental health services, as well as aged care assessments, community care programs and residential aged care. A better coordinated and integrated approach to health care system is important for all Australians and people with dementia are no exception. People who have complex needs (for example, acute psychiatric problems or intellectual disabilities) as well as dementia find it difficult to access appropriate care because of the division of responsibility for aged, mental health care and disabilities between the Australian Government and the State and Territory Governments.

a) Increased investment in dementia research

Investment in dementia research, whether in cause, cure or care, should be a key approach to mitigating the effects of the dementia epidemic. Less than 0.6% of the total annual cost of dementia care in Australia is spent on dementia research.¹⁴ This is an inadequate investment for the future given the very real economic and human costs of dementia. The returns from investment in research could be great. Historically, medical research in Australia has produced returns of \$5 for every \$1 spent.¹⁵ Warren Hogan in his *Review of Pricing Arrangements in Residential Care* for the Howard Government described dementia as the ‘poor cousin’ when it came to research given current costs and predictions of the increased needs in the future.¹⁶ Investment in research needs to be lifted to a level where we have greater confidence that therapeutic interventions can be in place before the first baby boomers reach 75 years of age. The window of opportunity before 2020 is small, so it is important to invest in dementia research now.

b) The inclusion of dementia in national prevention awareness programs

There needs to be recognition by Health Ministers of the potential for reducing the risk of dementia. Preventive efforts are critical in conditions such as dementia, where there is no established cure. Unlike other chronic diseases, there has been no major public awareness campaign to promote a wider community understanding of dementia, and its implications, how people with dementia might be supported, and approaches to reducing the risk of dementia. National prevention awareness programs should take into account the common risk factors associated with dementia and other chronic conditions.

There is strong evidence to suggest that the risk of developing dementia may be reduced and onset of dementia delayed by health and lifestyle choices. Some of these preventive factors include a healthy diet, reducing hypertension, lowering cholesterol, and promoting physical

¹⁴ Lee-Fay Low, Lisa Gomes, Henry Brodaty, “Australian Dementia Research: Current status, future directions” (Alzheimer’s Australia, to be published in June 2008)

¹⁵ Access Economics Exceptional returns: the value of investing in health: R&D in Australia, Canberra: The Australian Society for Medical research.

¹⁶ Warren Hogan, *Review of Pricing Arrangements in Residential Aged Care*. Commonwealth of Australia 9.8

and cognitive activity. Cardiovascular risk factors in particular, including diabetes, high cholesterol, and hypertension in midlife, have been shown to increase the risk of dementia by 20 – 40%. Smoking and excessive consumption of alcohol have also been reported to increase the risk of developing dementia.¹⁷ It is important that people are informed of the impact their health choices may have on their brains, as well as on other aspects of their physical health.

c) Taking measures to promote early diagnosis

For many years, the issue of most concern for people with dementia and their families and carers has been the trauma and uncertainty they suffer from a failure by some doctors to recognise dementia. GPs are often the initial contact for those in the earlier stages of dementia and they play a vital role in referral to specialised medical services and support services.

There is an urgent need to:

- ⇒ Improve diagnostic skills and ongoing assessment and management, for people with concerns about their memories.
- ⇒ Improve care planning, treatment, management and referral for people with dementia.
- ⇒ Increase awareness of best practice in dementia care.
- ⇒ Support and encourage multi-disciplinary care.

There is much potential for assisting GPs to attend more effectively to the needs of people at this vulnerable stage. This is particularly so for GPs who may not have the benefits of access to specialised services such as memory clinics or geriatricians, for example, those in some rural regions. New initiatives, such as teleconferencing, may provide support for GPs who are more isolated.

Developing a better and more accurate method of diagnosis is an important focus of research. Currently there is no single test that can accurately diagnose dementia. Use of dementia screening instruments, depression screening instruments, and tests for reversible causes of cognitive impairment and delirium, are important steps in the diagnostic process.

A national dementia awareness campaign would help the community to be more aware of the early symptoms of dementia. Dementia is not a natural part of ageing and the community needs to understand this so that cognitive changes and other symptoms of dementia are recognised earlier.

IT IS RECOMMENDED THAT:

1) Federal funding for community care for people over 65 years should be doubled over 5 years from the 2008-09 estimate of \$2 billion (which is only 24% of the total Commonwealth aged care budget) to \$ 4 billion

From a consumer perspective, the hospital and residential care systems will not work effectively until they are underpinned by community services that are resourced to assist people to stay longer at home, and to move back from institutional care to the community.¹⁸

¹⁷ Alzheimer's Australia "Dementia Risk Reduction: The Evidence" (Paper No. 13, Alzheimer's Australia, 2007) available at <http://www.alzheimers.org.au/upload/RiskReductionSept07.pdf>

¹⁸ See, National Consumer Committee, "National Dementia Manifesto 2007-2010" (Alzheimer's Australia, 2007) for further consumer priorities, available at <http://www.alzheimers.org.au/upload/Manifesto0710.pdf>

The health debate in Australia has been dominated by the roles of hospitals and residential care in respect of the care of older people. A significant increase is needed in the level of community care being provided.

The current balance of care provision is unduly skewed towards residential care. At the present time some 69% of the aged care budget of the Department of Health and Ageing is spent on residential care. Community care still represents less than 25% of aged care expenditure and has done so since the early 1990s. Carers Australia estimates that more than 400,000 Australians living at home have unmet needs for community care.¹⁹

Community care is the cornerstone of the health and aged care system in supporting carers. A report by Access Economics indicates that the replacement value of work by family carers would be \$30.5 billion, which is equivalent to 3.5% of forecast GDP and 62.2% of other formal health care²⁰

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. This heightens the importance of community support including on-going access to both planned and emergency respite services.

2) Residential and community programs be indexed to reflect real cost increases.

Current indexation against the Commonwealth Own Purpose Outlays index does not adequately take into account the increasing cost of wages in the sector, nor the increasing scarcity of skilled staff. Community care is particularly badly off as it does not receive the Conditional Adjustment Payment (CAP) paid to residential care providers.

3. Measures be taken to recognize the special needs of people with dementia

a) Flexible respite care services embracing the principle of CDC

Despite increased Government funding of respite, access to flexible quality respite care continues to be a problem for family carers. This is particularly the case for people from culturally and linguistically diverse backgrounds, and people in rural and remote areas.

People with dementia progressively lose many of the relationships on which their lives have been built as well as the capacity to engage in normal activities. Respite services should promote social engagement in activities that have been part of individual lives before diagnosis. Flexible respite care services embracing the principle of CDC would make this possible.

Under the National Respite for Carers Program, brokerage funds could be allocated to carers to enable them to select for themselves the respite most appropriate for their needs. To avoid the carer having to be responsible for handling the payments, the funds could continue to be administered through Carer Respite Centres, which would also provide information on available respite services.

Care recipients who wished to access respite services subsidised under HACC, the National Respite for Carers Program, or the Residential Aged Care Program, would still be able to do so. The budget allocated to the carer/care recipient would be solely in regard to the brokerage funds.

¹⁹ Carer's Australia "The Future of Community Care" (Report to the Community Care Coalition, 2007) vii

²⁰ Access Economics, "The Economic value of Informal Care" (Report for Carer's Australia, 2005) i

Not everyone would chose this option. However, for those who do, there would be considerable advantages in being able to obtain respite care consistent with their cultural and social background, or special care needs.

b) Expansion of Dementia Extended Aged Care at Home Packages.

The Extended Aged Care at Home – Dementia Program provides high-level care for people with dementia who have behaviours of concern. It is an individually tailored package to assist a person with dementia to remain in their home for as long as possible, if this is their preference. Consumers have been very supportive of the EACHD program. Currently there are only 2,000 dementia specific EACH places across Australia. There is a need for many more.

c) Provision for those with psychiatric illnesses or intellectual disabilities as well as dementia.

People with acute psychiatric problems or intellectual disabilities as well as dementia find it difficult to access appropriate care because of the division of responsibility for aged and mental health care between the Australian Government and State and Territory Governments.

4) Increase the funding available to aged care assessment teams so that waiting times for assessment are reduced and so that older people have access to advice on planning ahead.

Aged Care Assessment Teams (ACAT) provide advice to people with dementia and their family carers and help to secure access to care. There is evidence to suggest that older people value the services of ACATs. The ACATs also protect the integrity of a \$5 billion Commonwealth Aged Care Program. Current funding of ACAT represents about 1.5% of residential care outlays – an investment that should be increased to reduce delays in assessment.

The ACATs have played a crucial role in reducing inappropriate entry to residential care. Hal Kendig and Stephen Duckett highlight that, “in the early 1980s, before they were introduced, up to a third of nursing home residents were estimated to not have sufficient dependency to warrant their living there.”²¹

5) Investment in dementia research be increased to \$36 million p.a. and maintained at 1.5% of the direct cost of dementia or about \$36m p.a.

Investment in dementia research, whether in cause, cure or care, is a key strategy for addressing the dementia epidemic. Historically, medical research in Australia has produced returns of \$5 for every \$1 spent. Economic modelling has shown that if the onset of dementia could be delayed by 5 years there would be significant savings to the health and care system. Australian researchers have contributed significantly to the global effort in dementia research and are world leaders in research on the aetiology of dementia, epidemiology, carers, and dementia management.

²¹ Hal Kendig and Stephen Duckett, Australian directions in aged care: the generation of policies for generations of older people (Sydney, Australian Health Policy Institute, 2001/05)

Relative to current disease burden and current direct cost of care, dementia research in Australia is significantly under-funded. Annual expenditure on dementia research is currently \$12.8 million (0.57% of the total direct cost of dementia). In comparison with other major diseases, this is about:

- 50% of research funding for cancer, relative to current disease burden.
- 30% of research funding for cardiovascular disease, relative to current direct cost of care.
- 20% of research funding for cancer and diabetes, relative to current direct cost of care.
- 5% of current research funding for cancer relative to predicted direct cost of care in 2023.²²

6) Measures be introduced to achieve early diagnosis include providing incentives to GPs to up skill and introducing memory clinics on the model of Cognitive, Dementia and Memory Service in Victoria. These measures are critical because:

- a) 18 months or more for a diagnosis of dementia is not acceptable.**
- b) Early diagnosis offers the best opportunity to treat the symptoms of dementia, and allows time for financial and legal planning.**
- c) For younger people with dementia the process of diagnosis can be even more traumatic.**

Early diagnosis offers the best opportunity to treat the symptoms of dementia and most research confirms that early diagnosis is extremely important in order to arrest progression of the condition.²³ Early diagnosis can maximise the possibility that families and carers receive counselling and support in the early stages of the disease and have an increased understanding of changed behaviours. There is evidence to suggest that programs that aim to alleviate the difficulties associated with being a carer of a person with dementia can improve health-related quality of life²⁴ and delay institutional care.²⁵ Early intervention appears to increase a carer's use of strategies in coping²⁶ and can also assist the person with dementia to maintain independence and quality of life.

People with dementia will, at some stage of their dementia, lose decision-making ability and therefore it is critical that people with dementia receive an early diagnosis so that they have time for financial and legal planning before they lose this ability.

The risk of not intervening early is that a number of potentially treatable conditions, including depression and delirium that can resemble dementia or coexist with dementia, do not receive medical attention.

Research indicates that over 94% of Australians would seek help from their general practitioners if they were concerned about their loss of memory or changed behaviour.²⁷

²² Lee-Fay Low, Lisa Gomes, Henry Brodaty, "Australian Dementia Research: Current status, future directions" (Alzheimer's Australia, to be published in June 2008)

²³ Alzheimer's Australia "Diagnosing Dementia" (Reference Paper, 2001) available at <http://www.alzheimers.org.au/upload/DiagnosingDementia.pdf>

²⁴ D. LoGiudice, et al., "Do memory clinics improve the quality of life of carers? A randomized pilot trial". (1999) International Journal of Geriatric Psychiatry 626-632

²⁵ Henry Brodaty, M. Gresham, and G. Luscombe, "The Prince Henry Hospital dementia caregivers training programme" (1998) International Journal of Geriatric Psychiatry, 183-192.

²⁶ Henry Brodaty, M. Gresham, "Effect of a training programme to reduce stress in carers of patients with dementia." (1989) British Medical Journal 1375- 1379.

²⁷ National Consumer Committee, "National Dementia Manifesto 2007-2010" (Alzheimer's Australia, 2007)

Therefore upskilling GPs is a number one priority in improving the early diagnosis of dementia. 18 months or more for a diagnosis of dementia is not acceptable.

Cognitive, Dementia and Memory Services were developed by the Victorian Government in recognition of the need to provide a specialist multidisciplinary diagnostic, referral and educational service for people experiencing memory loss, or changes to their thinking, and for those who care about them²⁸ Diagnosing dementia is a complex process and implementing similar services would assist people to obtain a timely and accurate diagnosis and as a consequence have time to determine appropriate treatment needs and to plan for the future.

There are some 10,000 people with dementia in Australia who are under the age of sixty-five, and this group of people experiences even more serious delays in diagnosis compared with their older counterparts. Younger people with dementia are more likely to rapidly decline through the stages of dementia than older people, and as a result may not live as long as older people diagnosed with the condition. Therefore early diagnosis of younger onset dementia is critical, and this will only come with increased awareness of younger onset dementia within the health sector and the community more generally.²⁹

7) An awareness program be funded on the basis of Mind your Mind to promote lifestyle changes consistent with reducing the risk of dementia.

If the average onset of Alzheimer's disease was reduced by 5 years from 2005, then there would be 35% fewer new cases of dementia by 2020, cumulative savings of \$13.5 billion would be realised.³⁰

Alzheimer's Australia has developed **Mind your Mind**[®] a public education program designed to promote awareness of the lifestyle changes that may reduce the risk of dementia. By following the seven **Mind your Mind**[®] signposts, people are not only reducing the risk of developing dementia, they are leading healthier lifestyles.³¹

The Australian Government should commit to rolling *Mind your Mind* out as a national program. Efforts to educate the community about prevention and risk may have a marked impact on the future prevalence of dementia and should form a critical part of the government's priority of promoting and maintaining good health.

8) Measures to improve care for people with dementia in hospitals

a) Resourcing for coordinators to assist and train other hospital staff in respect of dementia care.

Without changes in the medical management of dementia over the next 25 years, the number of separations for people with dementia will quadruple due to population ageing.³² This data highlights the necessity for hospital staff to be adequately trained in dementia care, not only to improve quality of care, but also to enable staff to manage people's cognitive disabilities

²⁸ State Government of Victoria, Department of Human Services, Cognitive, Dementia and Memory Service, CDAMs (2008) <http://www.health.vic.gov.au/subacute/cdams.htm>

²⁹ For more information on diagnosis of younger onset dementia, see a paper prepared by the Melbourne Neurosychiatry Centre, "Understanding Younger Onset Dementia" Quality Dementia Series (Alzheimer's Australia, 2008) available at http://www.alzheimers.org.au/upload/QDC_YOD.pdf

³⁰ Access Economics "Delaying the onset of Alzheimer's Disease: Projections and Issues" (Report for Alzheimer's Australia, 2004) available at <http://www.alzheimers.org.au/upload/DelayingOnsetAccessEconomicsAugust2004.pdf>

³¹ For more information on Mind your Mind, see <http://www.alzheimers.org.au/upload/Brochure.pdf>

³² Australian Institute of Health and Welfare Dementia in Australia: national data analysis and development (Canberra, Australian Institute of Health and Welfare: 2007) 201

appropriately and efficiently.

People with dementia in hospitals are associated both with a longer length of stay and with higher per capita cost. In 2003-2004, the admitted patient expenditure due to dementia or Alzheimer's disease (regardless of principal diagnosis) was \$150.5 million.³³ Studies from several countries with different health care systems have demonstrated higher total costs of care for people with dementia compared with matched controls. Dementia also complicates other co-morbid conditions.

b) Promotion of new approaches to providing hospital care in the home or in residential care where it is possible to avoid moving the person.

In order to avoid unnecessary hospitalization, people with dementia need to be able to receive more complex health care in non-acute settings than is now the case.

Because of factors such as confusion and communication problems, people with dementia are rendered more vulnerable in acute care environments. There is evidence to suggest that hospitals can be unfriendly and dangerous places for people with dementia.³⁴ It is better, whenever possible, for people with dementia to remain where they are already receiving care, rather than being transferred to an acute care (e.g. hospital) setting.³⁵

Adverse events are more likely to affect a person with dementia in hospital because of poor compliance with interventions, together with an inability to recognise that a problem exists or call for help in situations in which a person *without* a cognitive impairment would call for help.

Alzheimer's Australia supports the implementation, where appropriate, of alternatives to hospital care, whether in the home or in residential care.

9) Implementation of a symbol for cognitive impairment on the basis of the report funded by the Department of Health from Alzheimer's Australia

The Dementia Symbol Research Project was undertaken by Alzheimer's Australia, funded by the Australian Government, and in partnership with Queensland University of Technology. The project's mandate was to investigate the viability and impact of a symbol in various care settings as well as within the broader community. This was achieved through four components of research: a systematic literature review, eight focus groups with key stakeholders, surveys conducted in a group format with people with dementia and family carers, and a Delphi research process involving twenty-two dementia experts.

The findings were that there is strong support for the adoption and implementation of a symbol within defined criteria and within particular environments. The purpose of the symbol was seen to differ within various domains. In the community and in the provision of general public services, it would serve as an indicator for "possible help needed". For emergency services, the symbol would facilitate rapid communication and appropriate use of protocols for response. In community, transitional and acute care settings the symbol would indicate the need for quality dementia care.

³³ Australian Institute of Health and Welfare Dementia in Australia: national data analysis and development (Canberra, Australian institute of Health and Welfare: 2007) 201

³⁴ Judith C Finn, Leon Flicker, Eileen Mackenzie et al "Interface between residential aged care facilities and a teaching hospital emergency department in Western Australia" (2006) 184 (9) The Medical Journal of Australia 432-435

³⁵ Margot Strachan, Sue Jarrad, Alan Nankivell, "Issues and initiatives in Acute Care in South Australia" (Alzheimer's Australia SA, 2003) available at <http://www.alzheimers.org.au/upload/IssuesInitiativesAcuteCare.pdf>

Despite some concerns of possible stigmatization, labeling, and increased vulnerability, most participants agreed that the wishes of people with dementia, and their family carers, should be paramount in any decision-making regarding the symbol.

Based on the research, a report has been submitted recommending that a national symbol should be adopted for cognitive impairment so that it would be inclusive of causes other than dementia (eg delirium), and that it could be based on existing symbol such as the Ballarat Health Service Cognitive impairment Identifier. The use of a symbol must be voluntary in all instances.

10) Recognition of the needs of special groups

a) Younger Onset Dementia

People with younger onset dementia, and their family carers have unique and complex needs due to their stage of life. They may be bringing up children, financially supporting the family, and have life expectations which they need to dramatically revise.

In 2006, Alzheimer's Australia undertook a comprehensive consultation with people affected by younger onset dementia in all States and Territories, with funding by the Department of Health and Ageing under the Dementia as a National Health Priority Initiative.³⁶

The major issues facing these 10,000 Australians include:

- a) Access to appropriate services, including community care and residential care, particularly as younger people with dementia are often otherwise physically strong and healthy.
- b) Family responsibilities, including still actively raising a family.
- c) Needing to revise expectations of everyday life, such as work, finances, living arrangements, social and sexual relationships, and independence and responsibility for others.
- d) Being more likely to have a rarer form of dementia than older people.
- e) Having significant financial commitments.

b) People from Indigenous communities

It has not been widely understood that dementia is also a major health problem for Indigenous people. Recent research in the Kimberley region suggests that the prevalence rates of dementia among remote and rural Indigenous people could be 4-5 times higher than those in the general Australian community. Research is now being funded in respect of those Indigenous people living in urban areas.

The evidence for the high prevalence rate of dementia among rural and remote Indigenous people is provided by the pioneering work of researchers engaged on the Dementia and Cognitive Impairment in Kimberley Indigenous Australians project. Of critical importance is increasing the awareness and understanding of dementia among Indigenous people. A National Indigenous Dementia Strategy has been developed to provide a framework for the action needed to address the issue of dementia among Indigenous people. Progress has been made but additional resources are needed to implement the strategy within Alzheimer's Australia and Indigenous organisations.³⁷

³⁶ Alzheimer's Australia, "Exploring the needs of younger people with dementia in Australia" 2007 available at <http://www.alzheimers.org.au/upload/YoungerOnset.pdf>

³⁷ Alzheimer's Australia, "Dementia, a major health problem for Indigenous people" (2007) Paper No.12 available at <http://alzheimers.org.au/upload/Indigenous.pdf>

c) People from rural and remote parts of Australia

Rural and remote communities face additional difficulties associated with population ageing and associated health problems when compared with their urban counterparts. Some of the obstacles for people with dementia and their family carers include longer distances to travel, lack of access to appropriate health services, poor distribution of specialists, and lack of appropriate understanding about dementia among health providers.

Last year, Alzheimer's Australia with funding from the Commonwealth Government undertook consultations in rural and remote areas; primarily in WA to gain an understanding of the support needs of people with dementia and their family carers in regional Australia.³⁸ Three key recommendations were made in the report, in order to enable rural and remote communities to cope with the increased numbers of people with dementia in the future.

1. Improve access to information and education on dementia in regional and remote areas through better utilization of local training providers and technology-based information channels.
2. Develop strategies to increase the numbers and retention rate of health professionals with expertise in dementia in regional and remote areas.
3. Explore processes for providing more flexible respite and residential care options in regional areas to overcome access barriers created by distance and location.

11) People with dementia should have the same opportunities as all Australians to have a say about their healthcare, now and for the future when they may become unable to express their choices for medical treatment. The current barriers are inconsistent, confusing and difficult legislation across Australia and lack of community education about advance care planning.³⁹

An increasing number of people with dementia who have not put enduring powers of attorney in place are referred to Guardianship Tribunals across Australia. Approximately 50% of all referrals relate to people with dementia. Advance planning could reduce not only this economic cost but also the social cost for people with dementia and their family carers.

Financial abuse is a major concern for older people. The Banking and Financial Services Ombudsman, which is an industry funded scheme, identified in their recent bulletin (56, December 2006) that 'Financial abuse of vulnerable older people has emerged as a National and International issue.' (p.2) One of the reasons for this, they state, is the, "projected increase in the number of people with dementia" (p.2). Advance Planning alleviates some of the potential for financial abuse by directly identifying the wishes of the person with dementia.

The Report of the House of Representatives Committee on Legal and Constitutional Affairs Inquiry into Older People and the Law contains important recommendations on advance planning. In the view of the National Consumer Committee of Alzheimer's Australia there are three key priorities that the Government should tackle:

1. Address Recommendation 26 of Older People and the Law: This recommends that the Australian Government acts on the third key priority of the National Framework for

³⁸ Alzheimer's Australia "Support needs of people living with dementia in rural and remote Australia" (2007)

³⁹ See, Alzheimer's Australia, "Decision making in advance. Reducing barriers and improving access to advance directives for people with dementia" (2006) Discussion paper 8, available at [Http://alzheimers.org.au/upload/Decision_making_in_Advance_may_2006.pdf](http://alzheimers.org.au/upload/Decision_making_in_Advance_may_2006.pdf)

Action on Dementia 2006-2010 which proposed that “jurisdictions refer the issues of legislative barriers regarding guardianship, advance care planning and advance care directives, wills and powers of attorney to Australian Government and State and Territories General Departments”. This priority was endorsed by the Health Ministers Conference in April 2006.

Co-operative Federalism is needed to overcome many of the legal barriers to people with dementia. The Older People and the Law Inquiry report recommends that initially the Standing Committee of Attorney-Generals should monitor the implementation of mutual recognition provisions of advance planning legislation.

2. Implement education and support programs for people with dementia and their families and carers, and the wider community to develop and use advance planning. This priority was identified in Recommendations 18 and 24 of Older People and the Law.
3. The provision of training for professionals who will be advising people on the legal, medical and social implications of their decisions. Recommendation 18 advocates a scheme to enable all powers of attorney to be prepared with the advice of a solicitor. Recommendation 27 encourages those with health care planning arrangements to inform their health care providers of their arrangements. This advice will not be helpful unless solicitors and doctors have adequate understanding of advance planning and its implications.

Implementing these recommendations from the Inquiry into Older People and the Law will give people with dementia a better opportunity to protect themselves and to make decisions about their future. These matters should be referred by Health Ministers to the Attorney-General as soon as is practicable so that the issue may be advanced within that Ministerial Council.