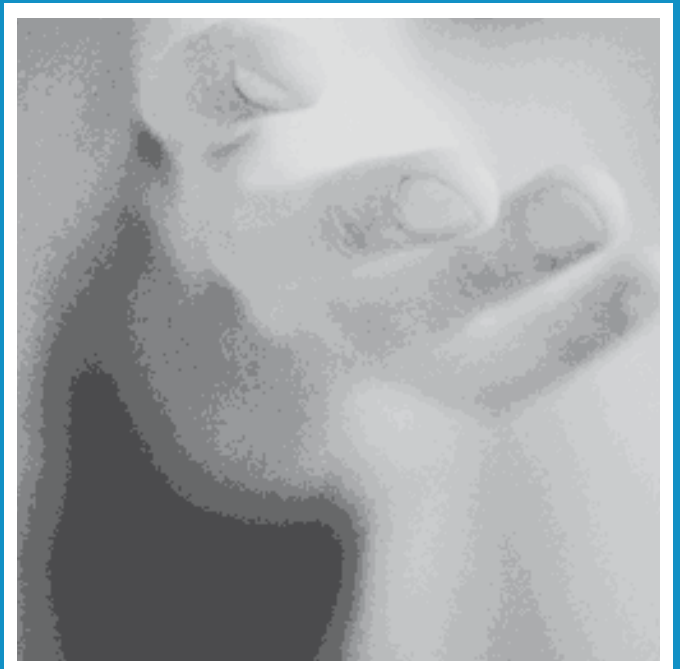




Australian Health Ministers' Conference

# National Framework for Action on Dementia

2006–2010



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SHPN (PHCP) 050135  
ISBN 0 7347 3857 9

May 2006

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# Foreword

Australia's ageing population presents many challenges and opportunities for our governments and communities. One of the most significant of these is the predicted increase in the numbers of people now and in the future who will be affected by dementia.

Currently around 200,000 Australians or 1 percent of the population have dementia. It is predicted that by 2016 dementia will be the major cause of disability for Australians, overtaking cardiovascular disease, cancer and depression. Some estimates suggest that by 2050, nearly three quarters of a million Australians, or almost 3 percent of the population, will have dementia.

Most jurisdictions already have policy and programs in place to address issues relating to ageing and dementia. Through the *National Framework for Action on Dementia 2006–2010*, Australian, State and Territory Governments have committed to working together and with other service providers and the community to deliver a coordinated, effective support system for people with dementia, their carers and families.

Chair  
Australian Health Ministers' Conference

In November 2003 my mother, Hazel Hawke went public with the news that she had Alzheimer's disease. Although she is naturally reticent about talking about her personal difficulties, she was drawn to the idea of going public if it would decrease the stigma of the disease and help others.

We are delighted to hear that the Australian Health Ministers have developed a National Framework for Action on Dementia. This is a great opportunity for people from all around Australia to work together, to make life better for people living with dementia and their families.

We hope that a National Framework will make a difference in both attitudes to dementia and care for people with dementia. No illness should carry a negative label. We also hope it will help to find ways to reduce the risk of people developing dementia.

Sue Pieters-Hawke

# Introduction

In January 2005, Australian Health Ministers jointly agreed to the development of a *National Framework for Action on Dementia 2006–2010* (the Framework). Developing the Framework has provided an opportunity to create a strategic, collaborative and cost-effective response to dementia across Australia.

Australian Health Ministers have led the development of the Framework working with Australian Community Services and Aged Care Ministers. The Framework is guided by a shared vision that seeks a better quality of life for people with dementia, their carers and families and identifies achievable goals for all Australian governments that will make a positive difference. The Framework recognises that this can only be achieved if people with dementia are valued and respected and the efforts of their carers and families are supported and encouraged.

The Australian Health Ministers have identified five key priority areas for inclusion in the Framework: care and support; access and equity; information and education; research; and workforce and training. These priority areas are fundamental to the quality of life of people with dementia as well as having the potential to yield the greatest benefits from the adoption of a national approach.

The Framework was developed in consultation with people with dementia, their carers and families, the peak bodies that represent them, key stakeholders, and service providers, and represents a shared national vision for action on dementia.

The *National Framework for Action on Dementia 2006–2010* looks beyond aged care to consider the health care and support dimensions of dementia. It focuses on outcomes that can best be achieved nationally, with the cooperation of the Australian, State and Territory Governments, rather than on any individual jurisdiction's initiatives. Housing and income support, while key issues, are outside the scope of the Framework.

The existing service system providing care and support to people with dementia, their carers and families is complex. Specialised and mainstream services offered through the health and aged care systems, and at times through the community care system, may present as a maze of options with inherent risks of service duplication and service gaps going unnoticed.

The Framework will help to coordinate existing dementia care and support activities and share good ideas through the provision of a structure that brings together the Australian Government and other jurisdictional strategies to treat, improve care for and delay the onset or progression of dementia. It will help develop a more responsive service system through commitment from Australian, State and Territory Governments to consistent outcomes while maintaining flexibility in service delivery.

# Understanding dementia and its impact

Dementia is a term used to describe a group of diseases that affect the brain and cause a progressive decline in the ability to think, remember and learn<sup>1</sup>. Dementia is not a single specific disease. Dementia affects people differently, and can impact differently on their carers and families.

Alzheimer's disease is the most common type of dementia, and accounts for more than 50 percent of dementia cases. The next most common form is vascular dementia, which causes around 20 percent of cases. Other types of dementia include frontal lobe dementia, Pick's disease, Lewy Body disease and alcohol-related dementia. People may also develop dementia in relation to other conditions including Parkinson's disease, Huntington's disease, Down syndrome and HIV/AIDS. These disorders of the brain produce symptoms that may include:

- memory loss
- language difficulties
- difficulty with understanding
- disorientation
- changes in mood, behaviour or personality
- hallucinations or delusions
- wandering behaviours.

Conditions with similar symptoms to dementia include stress, delirium, depression and the side effects of some medications, therefore early and accurate medical diagnosis is important where there seem to be changes in brain function.

Dementia is a growing health and social issue. The prevalence of dementia in Australia is anticipated to rise significantly over time<sup>2</sup>, as the proportion of older people in the population increases. People are living longer. The number of Australians over the age

of 65 will increase rapidly over the next 20 years as the 'baby boomers' reach retirement age. Although only about 1 percent of people aged 60–64 show symptoms of dementia, this increases to about 12 percent by age 80–84, and almost 40 percent of people aged over 94<sup>3</sup>.

Although most people with dementia are older, dementia is not a normal part of ageing. Dementia mostly affects people over the age of 70. It is uncommon in people under the age of 60, but can appear in people aged in their 40s or even younger.

Estimates suggest the number of people with dementia under the age of 65 will rise from about 9,990 in 2005 to 14,220 in 2020.

In Australia women on average tend to live around five years longer than men. As a result, women as a group have a higher prevalence of dementia than men. In 2005 women accounted for 61 percent of all people with dementia, but by 2050 this is predicted to fall slightly to 58 percent. This change in the gender mix of people with dementia has implications for service providers and planning for future dementia care and support, but is relatively small compared with the anticipated large rise in the total numbers.

Future projections of the numbers of people with dementia rest on a range of assumptions. These include the assumption that the age-specific historical rates summarised from research studies apply to Australia, and will continue to apply. It also assumes that there will be no improvement in our ability to prevent or cure dementia.

A great deal of progress has been made worldwide over recent years in understanding dementia, how to treat it and how to care for people at different stages of dementia. Despite these advances, the actual causes of

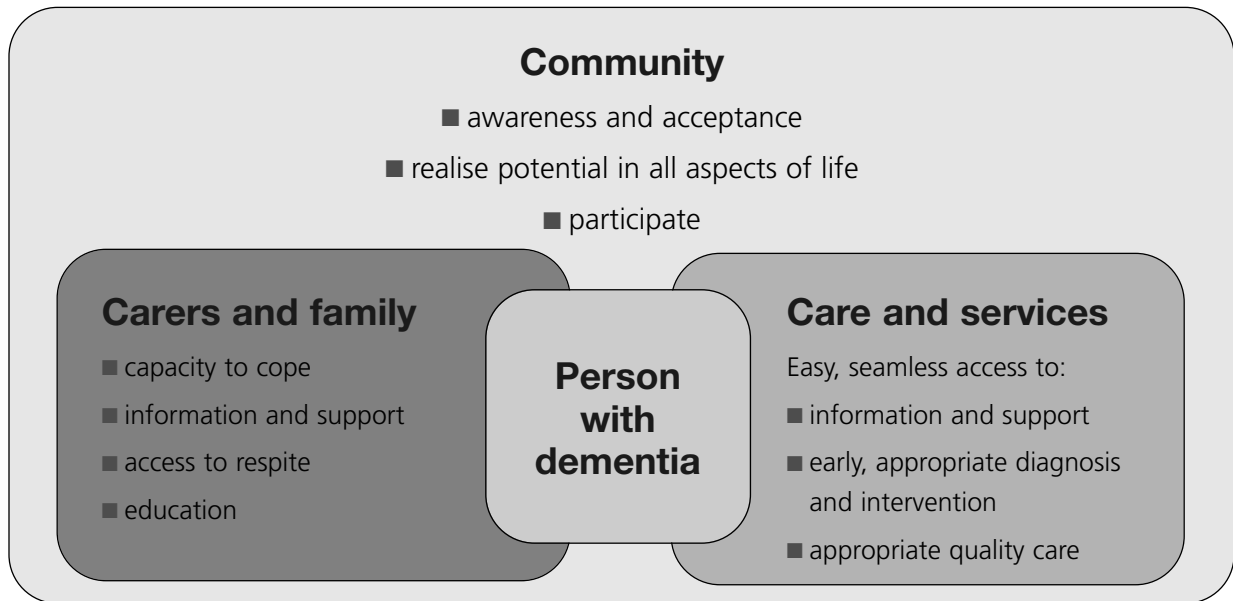
1 The World Health Organisation's International Classification of Diseases (2003) describes dementia as:

"Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain."

2 This prediction is based on certain assumptions, including: current demographic trends continuing; minimal advances in prevention, delay or reversal of certain dementias, such as Alzheimer's disease.

3 Access Economics. Dementia estimates and projections: Australian states and territories. Report for Alzheimer's Australia. February 2005 (Table 3). These estimates refer to moderate to severe dementia.

**A holistic model for living positively with dementia**



many dementias, including Alzheimer’s disease, remain a mystery. However, as clinicians and researchers continue to increase our understanding of dementia, there is growing optimism that it may eventually be possible to avoid, prevent, delay or more effectively treat dementia. New forms of support are also being developed for carers and the families of people with dementia.

It is clear that a variety of approaches is needed to better understand dementia. The general public, people with dementia, their carers and families want accurate and appropriate information about healthy ageing. They also want clinicians to be able to use effective and appropriate assessment tools to assess and screen people with dementia or who may develop dementia. Effort is needed to better understand both the causes of dementia and the needs of people with dementia.

Through the Australian Research Council and the National Health and Medical Research Council, the Australian Government funds dementia research that covers all aspects of medical, health and behavioural sciences and social services research. This research forms an important part of the general momentum that Australian Governments are encouraging around research on ageing. Mental functioning and age related disabilities, including neurodegenerative diseases, which cause dementia, have been identified as key research themes. Multi-disciplinary research has been encouraged on these subjects.

Recent research has revealed the significant role that genes or their biochemical pathways play in dementia. However, it remains unclear what contribution genes in and of themselves have in the development of dementia, as against genetic risk in conjunction with exposure to environmental risk factors. A number of forms of dementia have obvious causes, such as brain damage from substance abuse and trauma, dementia related to HIV infection, and vascular dementia.

Some research has suggested that factors that influence brain development or establish a cognitive reserve can impede the onset of Alzheimer’s disease. Such a cognitive reserve could potentially offer a protective mechanism for some forms of dementia<sup>4</sup>.

For dementia with clear-cut environmental causes, intervening to eliminate or reduce those causes would reduce the incidence of dementia. Thus general strategies to reduce substance abuse, trauma, and HIV infection, and

"Allow family members to recognise the possible early signs of memory loss in their loved one without fear, and encourage them to seek early diagnosis and treatment, rather than 'deny' the early signs, hoping they will pass, or that they can keep it a hidden secret, for fear of social rejection from their community"

*Carer feedback to consultation on the National Framework for Action on Dementia*

4 Bowden JD, Dementia Epidemiology Kukull WA, Department of Epidemiology, University of Washington (2002)

general strategies to improve vascular health, would all have a role to play in reducing the incidence of dementia.

In the particular case of Aboriginal and Torres Strait Islander people, general improvement of the social and emotional health and wellbeing of communities is needed, and this would have benefits for reducing dementia<sup>5</sup> from some particular causes. However, any increase in survival ultimately tends to increase the prevalence of dementia, simply because more people survive into the high-prevalence age groups.

At present, little is known about the prevalence and impact of dementia in Aboriginal and Torres Strait Islander communities. The review of the evidence by Pollitt<sup>5</sup> notes that the 'concept of dementia in old age in Australian Aboriginal and Torres Strait Islander communities is 'intrinsically paradoxical' as mortality is so high that few Aboriginal and Torres Strait Islander people reach old age. However, the higher morbidity rates, especially cardiovascular disease in Aboriginal and Torres Strait Islander people, suggest that dementia may pose a greater problem at earlier ages in these communities. This is consistent with a community survey<sup>6</sup> of Aboriginal people living in six small towns in North Queensland, which found dementia rates of 20 percent amongst the 133 Aboriginal people (3 percent of the Aboriginal population) aged over 65. Further research is required in order to plan and develop effective supports for Aboriginal and Torres Strait Islander people, their carers, families and communities.

People born overseas make up around 25 percent of the Australian population and 27 percent of Australian born people have at least one parent who was born overseas. Such statistics demonstrate that a significant proportion of the Australian population come from culturally and linguistically diverse (CALD) communities. People from these backgrounds have as equal a risk of developing dementia as others. However, people from CALD communities who have dementia may need services, information and support provided in a language other than English that can assist them to access support and care.

People with a mental illness or pre-existing cognitive disability who develop dementia while accounting for a relatively small percentage of all people with dementia, require specific planning to meet the greater level of need that arises from the added burden of disability dementia may impose.

"People with dementia for whom English is a second language regress to their original language and (like other people with dementia) relive their earlier life experiences. In many cases the memories from war and its associated trauma become vivid again".

*HACC worker feedback to Consultation on the National Framework for Action on Dementia*

People with Down syndrome have been found to have a dementia prevalence rate of between 20 and 55 percent in those aged 50 to 59 compared with a rate of 1 percent for the rest of the population<sup>7</sup>. Comprehensive linkages between dementia services and other parts of the health care and disability support systems are required to meet the needs of people with a dual diagnosis.

Dementia affects people and their families in many different ways. Some carers and people with dementia suggest that they often feel they are no longer valued. Because dementia affects people's physical and mental abilities it can produce strong negative reactions in others. This stigma associated with dementia can lead to people withdrawing from activities they enjoy and can eventually lead to social isolation and an increased risk of depression.

Dementia also has a major impact on the lives of those who care for people with dementia. Many people with dementia currently live in the community,

One moment you are a vital intimate partner in your relationships, the next you are merely a custodial obligation like a pet, a mortgage or yesterday's laundry...and expected to withdraw from the world's stage, assigned only the smallest walk-on parts."

*Feedback to the National Conference of Alzheimer's Australia (2001)*

5 Pollitt PA. The problem of dementia in Australian Aboriginal and Torres Strait Islander communities: An overview. *International Journal of Geriatric Psychiatry* 1997; 12:155-163.

6 Zann S. Identification of support, education and training needs of rural/ remote health care service providers involved in dementia care. Rural Health Support Education and Training (RHSET) project progress Report. Northern Regional Health Authority, Queensland – cited in Pollitt (5)

7 Zigman W, Schupf N, Haveman M, et al. The epidemiology of Alzheimer's disease in mental retardation: results and recommendations from an international conference *Journal of Intellectual Disability Research*. 1997; The quoted prevalences of dementia in people with Down syndrome are: 0-4 percent under 30 years of age; 2-33 percent for 30-39 years of age; 8-55 percent for 40-49 years of age; 20-55 percent for 50-59 years of age; 29-75 percent for 60-69 years of age.



supported by families and friends. Family members and carers may face real challenges in providing care and support, and people report that being a carer of a person with dementia can, at times, be an isolating and frustrating experience.

The need to support carers of people with dementia is crucial. However many people with dementia do not have a carer. There is growing evidence of an increase in single person households amongst older Australians. This is particularly true for older Australian women who, often as a result of outliving a spouse, live on their own in later years. There is a need to develop specific strategies to meet the needs of people with dementia who do not have a carer.

"Often the only 'friends' left are the paid carers. Family carers as a consequence often feel isolated as well as exhausted".

"Being a carer is like being on an emotional roller coaster"

*Feedback to the Consultation on the National Framework for Action on Dementia*

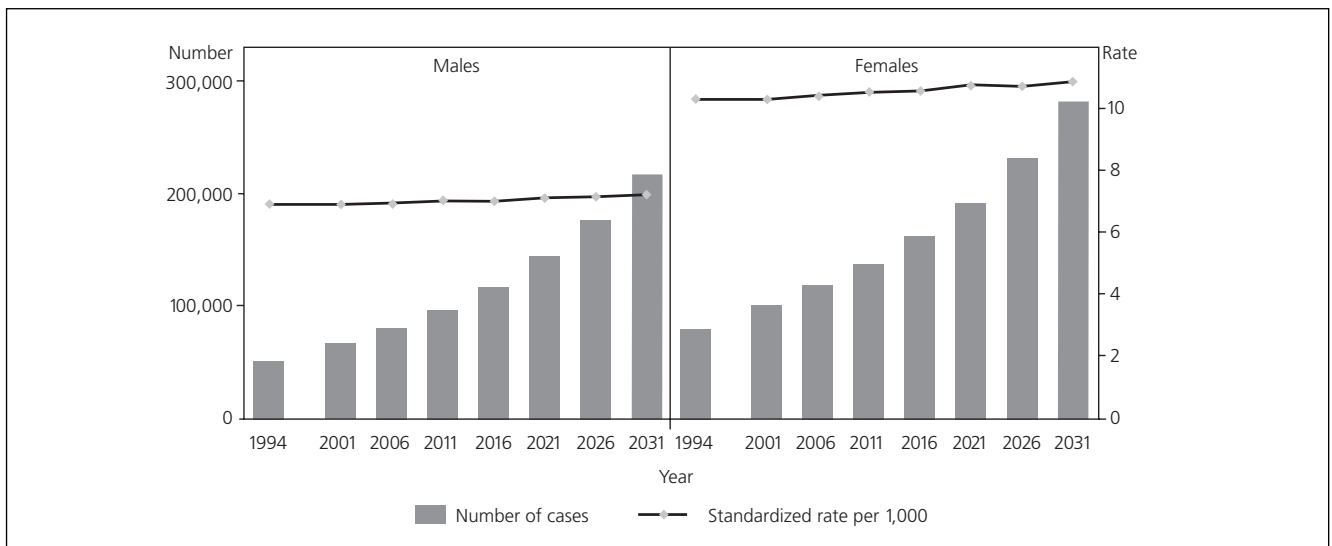
A report investigating the economic impact of dementia identified that in 2002 the Australian Government spent more than \$3.2 billion supporting people with dementia, with 88 percent of this money funding residential care placements. The report also identified that in 2002, over 5,000 Australians died prematurely as a result of complications related to dementia<sup>8</sup>.

It has been estimated that there are 40,000 more people with dementia now than in 2002. This represents nearly a 25 percent increase in dementia prevalence. Undoubtedly, this rise in prevalence is matched by the rising cost associated with caring for and supporting people with dementia.

"The significant change in prevalence estimates as a result of these factors underscores the sensitivity of the projections to such changes, lending caution to the interpretation and use of the forecasts. Indeed, more substantial events, such as research or treatment breakthroughs that enabled the delay of dementia onset, would produce substantial reductions in the future number of cases and in the real costs of dementia".

*Australian Bureau of Statistics*

### Change in prevalence for dementia, 1994 to 2031<sup>10</sup>



8 Access Economics (2003) The Dementia Epidemic: Economic Impact and Positive Solutions for Australia (Alzheimer's Australia).

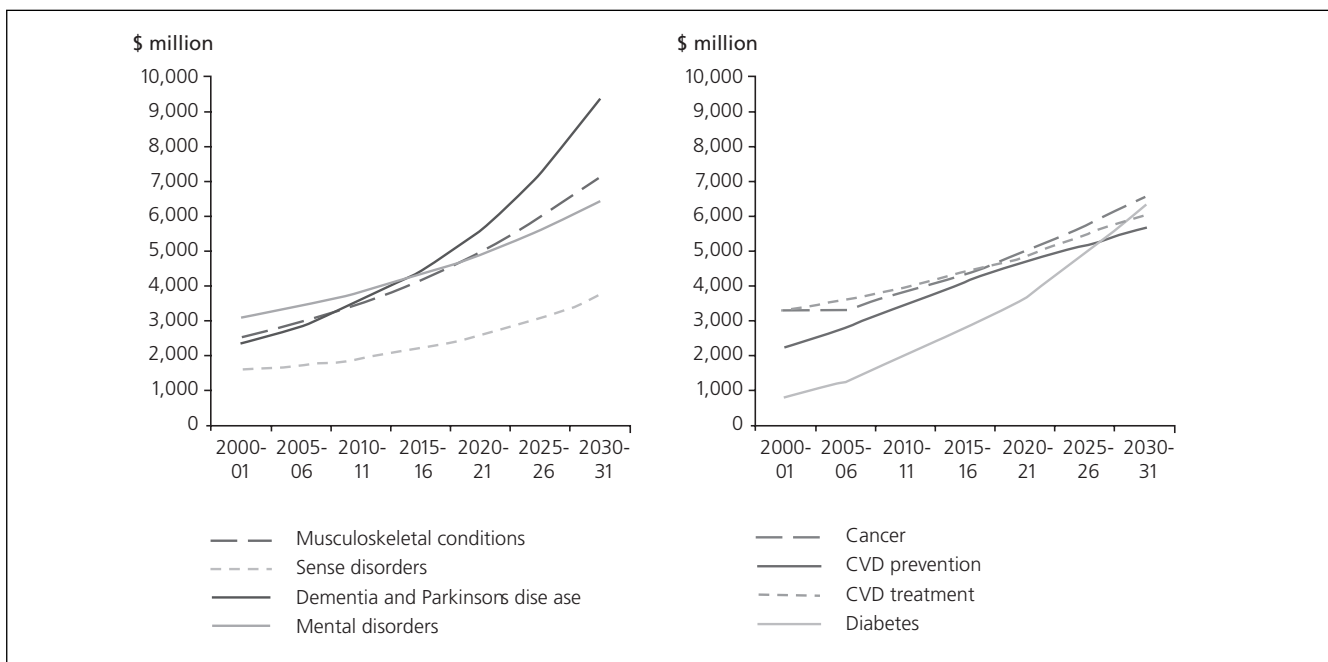
9 ibid

10 Vos, T, Goss, J, Begg, S, Mann, N. Unpublished paper Australian Burden of disease and injury study: Projected health care costs report. Unpublished report prepared by the University of Queensland and the Australian Institute of Health and Welfare for the Australian Government Department of Health and Ageing.

A large increase in health care costs, mostly driven by ageing and general population increases, is expected over the next 30 years. Ageing of the population in particular will have an increasing impact on expenditure for dementia in the next 30 years. The projected change in health expenditure for people with dementia and Parkinson’s disease from 2000–01 to 2030–31 is \$6.9 billion, from \$2.4 billion to \$9.3 billion. This represents the largest increase in

projected expenditure for this period for diseases identified as responsible for high disease burden. In comparison, mental disorders and cancer are projected to decrease as a proportion of GDP over the same period. Similarly there are continuing declines in mortality from cardiovascular disease, tobacco-related cancers, chronic obstructive pulmonary disease and alcohol related disease<sup>9</sup>.

**Change in total health expenditure (constant 2000–01 prices) for selected disease groups 2000–01 to 2030–31<sup>11</sup>**



<sup>11</sup> Vos, T, Goss, J, Begg, S, Mann, N. Unpublished paper Australian Burden of disease and injury study: Projected health care costs report. Unpublished report prepared by the University of Queensland and the Australian Institute of Health and Welfare for the Australian Government Department of Health and Ageing.

# Framework for action

## Vision, Objectives, Principles and Priorities for Action

The *National Framework for Action on Dementia 2006–2010* provides an overarching vision for Australia's dementia care and support system with clear objectives and principles that are supported by all Australian Governments. The five priority areas for action have been identified in consultation with people living with

dementia, their carers and families and other stakeholders and are fundamental to improving quality of life for people with dementia. For each of the priority areas there are outcomes, actions, a lead agency and key performance indicators that measure progress. The vision, objectives, principles and priorities for action are outlined below. The process used to develop the Framework and the actions in each priority area are detailed in the following pages.

### Vision

A better quality of life for people living with dementia and their carers and families.

### Objectives

Australians working together to make a positive difference to the lives of people with dementia, their carers and families.

Australian Governments, along with service providers and the broader community, working together to create an accessible, seamless pathway for people with dementia, their carers and families.

### Principles

1. People with dementia are valued and respected. Their right to dignity and quality of life is supported.
2. Carers and families are valued and supported and their efforts are recognised and encouraged.
3. People with dementia, their carers and families are central to making choices about care.
4. Service responses recognise peoples' individual journeys.
5. All people with dementia, their carers and families receive appropriate services that respond to their social, cultural or economic background, location and needs.
6. A well-trained supported workforce delivers quality care.
7. Communities play an important role in the quality of life of people with dementia, their carers and families.

### Priorities for Action

**Priority Area 1: Care and Support** services that are flexible and can respond to the changing needs of people with dementia, their carers and families.

**Priority Area 2: Access and Equity** to dementia information, support and care for all people with dementia, their carers and families regardless of their location or cultural background.

**Priority Area 3: Information and Education** that is evidence-based, accurate and provided in a timely and meaningful way.

**Priority Area 4: Research** into prevention, risk reduction and delaying the onset of dementia as well as into the needs of people with dementia, their carers and families.

**Priority Area 5: Workforce and Training** strategies that deliver skilled, high quality dementia care.

## Developing the National Framework for Action on Dementia

Australian Health Ministers met in January 2005 and agreed to the development of a national framework for action on dementia. A working group of officials from all jurisdictions was formed and developed a consultation paper<sup>12</sup>. The consultation paper was circulated widely from May 2005. States and Territories convened consultation forums and sought feedback from consumers, carers, peak bodies, industry and professional bodies.

Consultations culminated with a national forum, which was attended by around 70 stakeholders. This forum endorsed the development of the National Framework for Action on Dementia and supported the five key priority areas for action (care and support, access and equity, information and education, research, and workforce and training), which Health Ministers had previously identified.

The National Framework for Action on Dementia was developed by representatives from States and Territories and the Australian Government based on consultation feedback.

A range of government policies, strategies and priorities inform the *National Framework for Action on Dementia 2006–2010*. These include the Australian Government's programs and initiatives and State and Territory dementia plans. In turn, the Framework will assist in guiding the further policy developments of Australian governments.

The *National Action Plan for Dementia Care 1992–97* focused primarily on the community and residential

aged care system. Since then, other national policies and strategies have been developed for caring and supporting people with dementia, their carers and families.

In 2005, the Australian Government's *Helping people with dementia, and their carers – making dementia a National Health Priority 2005* budget measure focused on research, improved care initiatives and early intervention programs; Extended Aged Care at Home (EACH) dementia places; and dementia training for aged care and community workers.

Other national initiatives relating to broader health, ageing and community care issues that have influenced the development of the *National Framework for Action on Dementia 2006–2010* include:

- *A New Strategy for Community Care – The Way Forward* (2004)
- *National Palliative Care Strategy* (2000)
- *National Plan for Improving the Care of Older People across the Acute Care Continuum* (2004)
- *National Health Workforce Strategic Framework* (2004)
- *The National Mental Health Plan 2003–2008*
- *beyondblue*, National Depression Initiative (2000)
- *National Strategy for an Ageing Australia* (2001)

These initiatives have significant links with the *National Framework for Action on Dementia 2006–2010* (Table 1). Importantly the Framework seeks to build on established policy initiatives as well as highlighting where gaps in service delivery may be occurring.

**Table 1. National policy linkages with the Key Priority Areas**

Care and Support	Access and Equity	Information and Education	Research	Workforce and Training	
<i>National Palliative Care Strategy</i>	<i>National Plan for Improving the Care of Older People across the Acute Care Continuum</i> (2004)	<i>beyondblue</i> (2000)	<i>Building Ageing Research Capacity Project</i> (2001)	<i>National Aged Care Workforce Strategy</i> (2005)	
<i>A New Strategy for Community Care – The Way Forward</i> (2004)			<i>National Research Priorities</i> (2002) including <i>Promoting and Maintaining Good Health: sub categories; 'Ageing Well, Ageing Productively'; and 'Promoting Health and Preventing Disease'</i>		<i>National Health Workforce Strategic Framework</i> (2004)
<i>The National Mental Health Plan 2003–2008</i>					

12 Australian Health Ministers' Conference, National Framework for Action on Dementia, 2005 Consultation Paper.

The *National Framework for Action on Dementia 2006–2010* will build on a solid foundation of dementia plans developed by the States and Territories. In the context of these initiatives, the *National Framework for Action on Dementia 2006–2010* looks beyond aged care to consider the health care and support implications of dementia. It focuses on outcomes that can best be achieved nationally, with the cooperation of the Australian, State and Territory Governments, rather than on any individual jurisdiction's initiatives. A summary of state and territory dementia plans and the work of the Australian Government on dementia are located in the Appendix.

## Key Priority Areas

The following five key priority areas are fundamental to improving the quality of life of people with dementia, their families and carers, and are the focus of the *National Framework for Action on Dementia 2006–2010*:

1. Care and Support
2. Access and Equity
3. Information and Education
4. Research
5. Workforce and Training.

The Australian Government and States and Territories are working in close partnership to establish a framework to co-ordinate delivery of the most effective and responsive practices for care and support.

While most priority areas under the National Framework for Action on Dementia 2006–2010 are the collective responsibility of all governments, either the Australian Government or States and Territories will take the lead for key priorities for which they are primarily responsible. For example, the Australian Government has primary responsibility for residential aged care, and State and Territory Governments are primarily responsible for acute care services. Lead governments are indicated in the tables proceeding.

Actions in the tables below that are shaded have been identified as having immediate priority.

## Key Priority Area 1: Care and Support

### Outcomes

Effective, appropriate, quality and accessible care is provided:

- across all settings and geographical locations
- focusing on person centred planning
- through involving carers and family members
- allowing seamless transition for people with dementia between the different types of care.

### Challenges

- Diagnosis, assessment, care and support is fundamental to enhancing the quality of life for people with dementia, their carers and families. People with dementia and their carers require networks of care and support that are well coordinated with clear pathways between options that are flexible and respond to people's changing needs.
- Networks that plan care and support services for people with dementia need to operate at a local level with community participation in the planning process.
- Dementia specific versus mainstream care and support for people with dementia is a significant issue that requires further investigation. Access to dementia sensitive mainstream services is essential for people with dementia and their carers.
- More flexible approaches to supported accommodation in the home and in residential care facilities are required.
- Community Care Review provides opportunities to strengthen care and support for people with dementia.

### How will we know

- Improved availability of multidisciplinary and integrated care.
- Increased availability of models of care that meet the needs of individuals, carers and family members.

Shaded areas indicate actions with immediate priority

Priorities for action	Actions	Lead agency
Develop service plans to meet the needs of people with dementia, their carers and families. Include analysis of the potential impact of establishing dementia specific services and identify mechanisms to implement dementia sensitive practices into mainstream services.	Map service pathways at a national and state/territory level.	Australian Government
	Assess service gaps.	Australian Government and States and Territories
	Incorporate into service planning.	Australian Government and States and Territories
Develop and/or identify effective and appropriate cognitive assessment tools to assess and screen people with dementia or who may develop dementia.	Dementia addressed in community care review intake and comprehensive assessment processes.	Australian Government through Community Care Review
	Evaluate and validate a selection of existing diagnosis/assessment tools.	Australian Government and States and Territories
Work with appropriate accreditation bodies to incorporate dementia care standards.	Incorporate residential care standards.	Australian Government
	Incorporate community care standards.	Australian Government and States and Territories
	Incorporate acute care standards.	Australian Government and States and Territories
Primary Health: support primary health care professionals and encourage GPs to broaden their skills in identifying, referring and managing people with dementia.	Agreed approach for GPs in identifying, referring and managing over 75 age group.	Australian Government and States and Territories
	Assess results of University of Newcastle research into the detection and management of dementia in general practice, funded by NHMRC.	Australian Government and States and Territories
	Work with divisions of GPs and other primary care bodies to identify opportunities.	Australian Government and States and Territories
Community Care: identify and promote the best ways to assist people with dementia, their families and carers to navigate the community care system.	Provide information about care pathways available in plain English for people with dementia, their families and carers.	Australian Government and States and Territories
Respite Care: review, develop and promote flexible respite care models.	Ongoing development and implementation of flexible respite care options.	Australian Government and States and Territories
Acute Care: identify acute care services that are sensitive to people with dementia and the needs of their carers and families.	Review the applicability of the principles of the <i>From Hospital to Home Action Plan</i> , developed by the AHMAC Care of Older Australians Working Group.	NSW/VIC
	Develop dementia sensitive principles for Acute care services.	NSW/VIC

<b>Priorities for action</b>	<b>Actions</b>	<b>Lead agency</b>
Residential Care: plan to meet the demand for residential care places for people with dementia.	Project demand for residential care places for people with dementia.	Australian Government
	Increase places available to meet demand.	Australian Government
Palliative Care: develop workforce, education and training initiatives for health professionals and community care providers that inform them about palliative care and the needs of people with dementia.	Develop palliative care workforce, education and training initiatives for health professionals and community care providers.	Australian Government and States and Territories
Behavioural issues: identify and promote evidence based service models and funding arrangements for the assessment, management, support and accommodation of people with dementia and behavioural issues.	Identify evidence based service models and funding arrangements.	Australian Government and States and Territories
	Promote evidence based service models and funding arrangements.	Australian Government and States and Territories

## Key Priority Area 2: Access and Equity

### Outcomes

- All people with dementia, their carers and families should be able to obtain quality services that suit their needs, when they need them, regardless of where they live, their health status, their age, their cultural background, or financial and social circumstances.

### Challenges

- Many people with dementia and their carers report experiencing difficulties accessing adequate and appropriate support. For some it is their location in a rural or remote area that limits the availability

of care options. Others report that cultural and language barriers impact on their ability to access services and some people have their choices restricted due to financial limitations.

- Individuals or communities who may be disadvantaged in accessing information, care and/or support require additional attention. Better ways are needed to identify, assess and support all people with dementia particularly for individuals who may be disadvantaged when accessing services.

### How we will know

- Level of improvement of accessibility to care.

*Shaded areas indicate actions with immediate priority*

Priorities for action	Actions	Lead agency
Identify the specific barriers to the access of care and support including: <ul style="list-style-type: none"> <li>■ Aboriginal and Torres Strait Islander people</li> <li>■ Younger people</li> <li>■ People who are homeless</li> <li>■ People who are financially disadvantaged</li> <li>■ People without carers</li> <li>■ People with dementia and another cognitive impairment/ dual diagnosis</li> <li>■ People living in remote and rural locations</li> <li>■ People from culturally and linguistically diverse backgrounds</li> <li>■ People living alone</li> </ul>	Identify barriers to access.	Australian Government and States and Territories
	Share information across jurisdictions	Australian Government and States and Territories
Develop appropriate service models to meet the needs of diverse groups.	Develop service models.	Australian Government and States and Territories
Develop specific strategies within dementia plans and policies that are informed by the Australian Health Ministers' Advisory Council's <i>Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004–2009</i> .	Report progress to AHMAC.	Australian Government and States and Territories



## Key Priority Area 3: Information and Education

### Outcomes

- People with dementia, their carers and families can easily access appropriate information, education and support services.
- The community is aware and understands dementia and how to assist people with dementia, their carers and families.
- Information sharing between jurisdictions is effective.

### Challenges

- People with dementia, their carers and families need access to information and education that is accurate and provided in a useful, timely and

meaningful way. Carers require different information at different stages of dementia, including advice and guidance from professionals as well as information about the experiences of other carers.

- The need to support and recognise the emotional, psychological and physical needs of carers.

### How will we know

- Improved access to information and education about dementia.
- Increased community awareness of dementia.
- Availability of legal framework to enable inter-jurisdiction recognition of Guardianship, advance care planning and advance care directives, wills and powers of attorney.

*Shaded areas indicate actions with immediate priority*

Priorities for action	Actions	Lead agency
Refer the issues of legislative barriers regarding Guardianship, advance care planning and advance care directives, wills and powers of attorney to Australian Government, State and Territory Attorneys General Departments.	Considered by AHMC.	NSW
	Implement AHMC decisions.	Australian Government and States and Territories
Improve information sharing between jurisdictions.	Create mechanisms for regular information sharing opportunities.	Australian Government and States and Territories
Undertake community awareness programs based on agreed key messages including targeted information campaigns to specific community groups.	Undertake dementia literacy survey as a baseline of public awareness.	Australian Government
	Develop agreed key messages.	Australian Government and States and Territories
	Develop and undertake community awareness.	Australian Government and States and Territories
Increase the awareness of broader service provider network that interact with people with dementia and their carers eg Centrelink, police, pharmacies, transport workers, banks.	Develop awareness resources.	Australian Government and States and Territories
Establish links between specialist dementia information services and other information services.	Establish national linkages.	Australian Government
	Establish State and Territory linkages.	States and Territories
Jurisdictions have strategies in place to address elder abuse, including in relation to dementia.	Strategies in place.	States and Territories

## Key Priority Area 4: Research

### Outcomes

- Research is directed to the cause, cure and care of dementia.
- Research is translated into practice and is promoted and available to those who need it.
- Research findings are promoted more broadly in the community.

### Challenges

- A variety of approaches to research are needed to better understand dementia. The general public, people with dementia, their carers and families want accurate and appropriate information about healthy ageing. Effort is needed to better understand both the causes of dementia and the needs of people with dementia and their carers.

- Research is also needed into what support, care and education works best for groups with diverse needs such as:
  - Aboriginal and Torres Strait Islander people
  - Younger people
  - People who are homeless
  - People without carers
  - People with dementia and other cognitive impairments
  - People living in remote and rural locations
  - People from culturally and linguistically diverse backgrounds
  - People who are financially disadvantaged.

### How will we know

- Funds spent on dementia research as a percentage of total funds spent on health research nationally.
- Extent to which practice guidelines and service models are based on research findings.
- Level of dissemination of dementia research findings.

*Shaded areas indicate actions with immediate priority*

Priorities for action	Actions	Lead agency
Establish key areas for national research.	Establish mechanism for developing and reviewing key areas for national research.	Australian Government
	Identify key areas for national research.	Australian Government
	Review key areas for research	Australian Government
Promote and disseminate agreed key areas for research.	Disseminate to key stakeholders and workforce.	Australian Government and States and Territories
Identify current and new funding sources for dementia research on the agreed key research priorities.	Funding sources identified.	Australian Government
Promote the results of research including community, acute and residential care.	Identify and implement the most appropriate ways to promote the results of research.	Australian Government
Research the projected prevalence of dementia, including prevalence among groups with diverse needs.	Report findings.	Australian Government
Design and implement uniform and effective data standards and systems which can be used in all jurisdictions and which ensure dementia data items are included in key minimum data set (MDS).	Establish data standards.	Australian Government
	Implement data standards.	Australian Government and States and Territories
Translate research into practice.	Identify and implement the most appropriate ways to enhance existing practice.	Australian Government and States and Territories
	Enhance existing practice based on research findings.	Australian Government and States and Territories

## Key Priority Area 5: Workforce and Training

### Outcomes

- A skilled and informed workforce is available to care for and support people with dementia, their carers and families.

### Challenges

- A confident, informed and skilled workforce is essential for providing high quality dementia care. Attracting and retaining staff to work in dementia care is a significant challenge. Increasingly the health, community and aged care workforce needs to be able to respond to people with dementia.

- Diagnosis is essential for a person with dementia to be advised and supported to follow the most appropriate pathway, linkages and referrals for their needs. Unfortunately, in some rural and remote areas, and for some disadvantaged groups, diagnosis does not occur or is problematic given the existing limited distribution of diagnosticians.
- Review the incentives and disincentives for recruitment and retention of the dementia workforce.

### How will we know

- Increased access to education, training and information on dementia.
- Improved recruitment and retention of the aged care workforce.

*Shaded areas indicate actions with immediate priority*

Priorities for action	Actions	Lead agency
Identify and promote linkages between the Framework and national and jurisdiction workforce strategies including National Health Workforce Strategic Framework and the National Aged Care Workforce Strategy.	Identify and promote dementia related workforce issues.	Australian Government and States and Territories
Identify incentives and barriers to participation in dementia care and the incentives and disincentives for recruitment and retention of the dementia workforce.	Undertake review.	Australian Government and States and Territories
Include dementia in training and curricula for relevant health, community care and aged care professionals.	Seek cooperation from relevant agencies/bodies.	Australian Government and States and Territories
Promote flexible strategies for professional development such as Telehealth.	Develop and implement strategies.	Australian Government and States and Territories
Promote interdisciplinary professional development.	Identify and promote opportunities and benefits.	Australian Government and States and Territories
Develop resources and promote effective training strategies to manage challenging behaviours.	Identify existing resources.	Australian Government and States and Territories
	Develop new resources.	Australian Government
	Promote existing and new resources.	Australian Government and States and Territories

# Implementing and evaluating the framework

## Roles and Responsibilities

*The National Framework for Action on Dementia 2006–2010* is a national policy and implementation plan for a coordinated national approach to improve the quality of life of people living with dementia, their carers and families.

The Framework will significantly contribute to meeting the needs of people with dementia, their carers and families through a national approach to five priorities:

- improved care and support
- improved access and equity
- information and education
- promoting and encouraging relevant dementia research
- an appropriately skilled and supported workforce.

The Framework aims to implement these priorities by:

- endorsing a common set of principles to underpin policy, planning and service delivery for people with dementia, their families and carers
- reaching agreement on the most cost-effective means of jointly addressing key priorities for action on dementia
- considering opportunities for cost-sharing arrangements between governments to fund agreed priority areas that may include one-off projects and recurrent services
- reviewing existing dementia care and support services to develop an evidence base of best practice
- setting up a cooperative process for locally commissioned work and sharing information on best practices
- proposing nationally-agreed key areas for research relevant to the current needs in dementia care, and work with key stakeholders to support a dementia care research agenda
- agreeing a core data set and related definitions for dementia care and support services
- developing national quality standards for dementia care and support services to benchmark services, performance and outcomes

- negotiating a common process for monitoring, evaluating and reporting on improvements in dementia care and support services.

Underpinning the Framework is the recognition that a diverse range of government and non-government agencies have responsibility for providing services to people with dementia, their carers and families. The Australian Government and State and Territory Governments have responsibilities for providing services for people with dementia and play a key role in the development and implementation of dementia policies and programs.

There is much to be gained by continuing to strengthen relationships between the Australian Government and States and Territories governments, non-government organisations and consumers. Fostering a shared commitment with stakeholders will be a feature of the detailed implementation and evaluation strategy.

The *National Framework for Action on Dementia 2006–2010* and the Australian Government's 2005 Federal Budget initiative, *Helping people with dementia, and their carers – making dementia a National Health Priority* intersect in many areas. The area of research is one example of common priorities for action. Both initiatives advocate the importance of ongoing research into consumer care needs, best practice dementia care and service delivery models. The Framework is informed by, and will inform the development of, State and Territory dementia policy, programs and plans.

The Framework will allow everyone involved in providing dementia care and support, to share what they know about dementia and to work together to develop the best possible models of care. Stakeholders include people with dementia, their carers and families, different levels and areas of government, peak bodies, service providers, and health professionals.

The Framework is also intended to inform policy and service developments leading to more consistent, cost-effective approaches to dementia research, assessment, treatment and care, to minimise duplication of effort and funding.

The Framework provides an overarching structure that all Australian Governments have committed to implementing. For a range of historical and constitutional reasons the various levels of government in Australia have different obligations for service provision for people with dementia, their carers and families. For example, the Australian Government funds and monitors General Practitioner and residential aged care services, whereas State and Territory Governments have responsibility for primary and acute care services.

In developing the *National Framework for Action on Dementia 2006–2010* it was intended that a more coordinated and seamless transition for people with dementia between the various government services and programs be achieved.

## **Together the Australian Government, and State and Territory Governments will:**

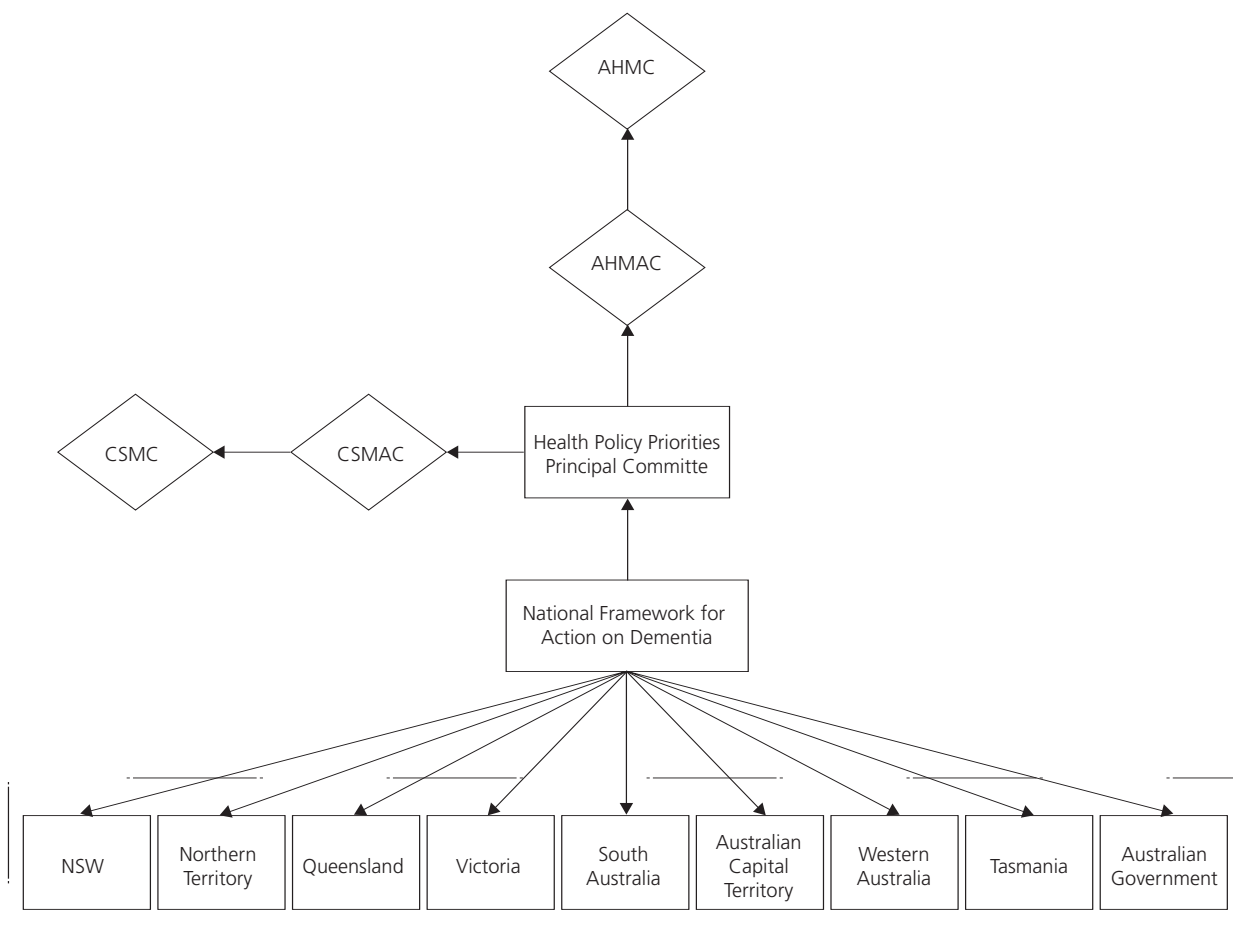
- Collaborate to work towards best practices in dementia care and support services with service agencies and community groups.
- Move towards the delivery of a seamless continuum of care and support services that respond to the changing needs of people with dementia.
- Collaborate to identify the conditions under which support services can be flexible and what types of services can best respond to individual needs.
- Ensure there are clear entry points for services that are sensitive to the needs of people with dementia.
- Work to improve integration of Australian Government funded health, aged and community care services that support people with dementia, their carers and families.
- Support the development and delivery of dementia curricula for training a range of health, aged and community care workers.
- Work co-operatively with service providers and consumers to encourage the adoption of the Framework.
- Work closely with the carers and families of people with dementia to provide appropriate support for carers, that recognises the emotional impact of caring for a person with dementia.
- Deliver services for people with dementia that are sensitive to the needs of individuals, their carers and their families, including people from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander people, younger people with dementia, and people living in rural and remote areas.
- Fund and monitor care and support services that assist people with dementia remain at home.
- Provide funding to enable promotion of comprehensive, accurate and accessible information about: advances in research on the causes of dementia; evidence-based best practice models of care and support; the rights and needs of people with dementia, their carers and families.
- Consult with peak dementia organisations and service providers in relation to government policy formulation around dementia and establish mechanisms to promote strong relationships.
- The Health Policy Priorities Principal Committee (HPPPC) will oversee the implementation of the *National Framework for Action on Dementia 2006–2010*. The HPPPC will report to Australian Health Ministers and will be responsible for:
  - Providing adequate and timely information to Health Ministers and Community Services Ministers regarding the implementation and evaluation of the *National Framework for Action on Dementia 2006–2010*.
  - Consulting with people with dementia, their carers and families as well as service providers and peak bodies that represent them on developments and initiatives of the *National Framework for Action on Dementia 2006–2010*.
  - Making recommendations to Governments regarding new information, research and emerging issues that relate to the lives of people with dementia.
  - Disseminating information and models of best practice for services for people with dementia, their carers and families between various jurisdictions.
  - Developing and implementing an evaluation strategy for the *National Framework for Action on Dementia 2006–2010*.

# Accountability and governance

The need for clear and transparent accountability regarding priorities for action emerged as a major theme from the national consultations with people with dementia, their carers and families, and service providers. Appropriate mechanisms are required to ensure accountability for resources and the achievement of outcomes. These mechanisms need to span sectors at both federal and state/territory level. Monitoring will

occur through the Australian Health Ministers Advisory Council (AHMAC) and the Australian Health Ministers Conference (AHMC). The Health Policy Priorities Principal Committee will be responsible to report to AHMAC and AHMC. Additional reports for information will be made to the Community Services Ministers Conference (Diagram 1), and other relevant State and Territory Ministers will be involved as appropriate.

**Diagram 1. National Framework for Action on Dementia Governance**



**Key:**

AHMC – Australian Health Ministers Conference  
 AHMAC – Australian Health Ministers’ Advisory Council

CSMC – Community Services Ministers Conference  
 CSMAC – Community Services Ministers’ Advisory Council

# Glossary

**Acute care** – care provided usually as a result of a medical crisis. Includes care provided in emergency departments and inpatient hospital care.

**Advance Care Directive** – (also termed “living will” or “refusal of treatment certificate”) document in some cases formal and legally endorsed that states instructions for the care to be implemented in the event of future decisional incapacity.

**Challenging behaviours** – disturbed behaviour that may include agitation, aggression or vocalisation that impacts on the care and quality of life of a person with dementia.

**CACP** – Community Aged Care Package, a package of services and assistance to support older people who live in the community.

**Care pathway** – an individual's journey through the care system.

**Care coordination** – identifying care and support options and strategically planning a person's care.

**Community care** – care that is provided to a person in their community as opposed to care that is provided in a residential facility.

**Carer** – usually a family member or friend. Their work is based on a pre-existing relationship and is unpaid and often unrecognised. The primary carer is the person who has provided the most assistance to the person in relation to self-care, mobility and communication, and other needs.

**Delirium** – disturbances of consciousness and attention, perception, thinking, memory, psychomotor behaviour, emotion, and the sleep-wake cycle. It may occur at any age but is most common after the age of 60 years. The delirious state is transient and of fluctuating intensity; most people recover within four weeks or less.

**Dementia** - a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded.

**Depression** – a mood disorder that presents as a pervasive and relentless sense of despair. A lack of interest in life, weight loss, loss of appetite, feelings of uselessness and sleep disturbance are some of the more common symptoms.

**Dual diagnosis** – the co-existence of two or more conditions such as Down syndrome and Dementia.

**EACH** – Extended Aged Care at Home Package, can include a range of care and support services for people with dementia who want to remain living at home.

**EPC** – Enhanced Primary Care.

**Evidence based** – practices that are informed and supported by reputable research and knowledge bases.

**Geriatric medicine** – refers to specialist medical services that assess and treat illnesses in older people, usually over the age of 65.

**HACC** – Home and Community Care services

**Incidence of dementia** – the number of new people diagnosed with dementia each year.

**Journey** – refers to the journey people with dementia, their carers and families may take as they and their loved ones progress through the stages of dementia.

**Multi-disciplinary team** – teams that may contain general practitioners, nurses, assistants in nursing, geriatricians, psycho geriatricians, nurse practitioners, occupational therapists, speech pathologists, social workers, pharmacists, psychologists, mental health workers, and other practitioners working together to deliver assessment services and integrated health care.

**Person centred** – planning or service provision informed by the needs, wishes and preferences of a person with dementia.

**Prevalence of dementia** – the number of people with dementia.

**Primary care** – services provided by GPs, nurses, community nurses and aged care assessment teams. Includes assessment, diagnosis and treatment services.

**Quality of life** – an individual’s perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating the person’s physical health and psychological state, level of independence, social relationships, personal beliefs and relationship to salient features in the environment.

**Residential care** – care provided in an aged care facility, such as a nursing home or hostel.

**Respite** – temporary care arrangements provided by someone other than the usual carer, also includes short-term residential care.

**Telehealth**– medical services provided electronically, for example via telephone or videoconferencing facilities.

**Workforce** – refers to all people employed who provide assistance, care, information or support to people with dementia, their carers or families.



# Appendix

## Australian Government, and State and Territory Plans supporting people living with dementia, their carers and families

### Australian Government

- \$2.3 billion annually to support people with dementia and their carers and families. This includes \$268m to support people with dementia living in the community through funding Home and Community Care services, Community Aged Care Packages (CACPs), dementia specific respite services under the National Respite for Carers Program (NRCP) and Extended Age Care at Home Packages (EACH).
- Funding for the National Cross-Cultural Dementia Network and for a dementia-training package for Aboriginal and Torres Strait Islanders.
- Developed a range of research and workforce training initiatives such as the Building Ageing Research Capacity (BARC) Project and the National Aged Care Workforce Strategy.

### Australian Capital Territory

- *The Health Action Plan 2002* promoting healthy ageing, services for the frail aged and older people with cognitive impairment and post acute care as priorities for health services.
- Clinical Services Plan promotes and outlines rehabilitation services and psycho-geriatric care programs.

### New South Wales

- *Future Directions*, the second NSW dementia strategy, a collaborative plan between NSW Health and the NSW Department of Ageing, Disability and Home Care includes:
  - Dementia Advisory Services across NSW
  - Mind Your Memory initiative
  - Dementia Care Clinical Nurse Consultants in key areas.

[www.health.nsw.gov.au/policy/hsp/publications/dementia/future\\_directions.pdf](http://www.health.nsw.gov.au/policy/hsp/publications/dementia/future_directions.pdf)

### Northern Territory

The Northern Territory Department of Health, Ageing and Disability has undertaken a number of initiatives which have relevance for people with dementia who live in the Northern Territory:

- Validation project for the Kimberley Indigenous Cognitive Assessment tool (KICA).
- Reviewing local policies for Age Care Assessment Teams.
- Development of strategies for recruitment and retention for the age care workforce.

### Queensland

Dementia care is addressed specifically as one of the seven priority areas of Queensland Health's *Directions for Aged Care 2004–2011*.

Dementia care has five focus areas:

- Assessment
- Access
- Service delivery
- Carers
- Partnerships.

Another key priority addresses the needs of older Aboriginal and Torres Strait Islander peoples.

[www.health.qld.gov.au/acru/aged\\_care/PDFs/287817\\_ACCRU\\_5.pdf](http://www.health.qld.gov.au/acru/aged_care/PDFs/287817_ACCRU_5.pdf)

### South Australia

South Australia's Department of Families and Communities is currently developing a State Dementia Plan, which emphasises the need for coordinated services, prevention and primary care services, and improving the quality and safety in dementia services. This will link to the Strategy for an Ageing South Australia currently being developed.

## Tasmania

The Tasmanian *Dementia Care Plan 2000 and Beyond* is currently being reviewed. Key elements of the plan included:

- Information, education and community awareness
- Planning for loss of competency
- Diagnosis, ongoing assessment and coordination
- Training
- Access to services.

[www.dhhs.tas.gov.au/dementiacare/pdfs/dhhs\\_dementiacareplan.pdf](http://www.dhhs.tas.gov.au/dementiacare/pdfs/dhhs_dementiacareplan.pdf)

## Victoria

*Pathways to the Future, 2006 and Beyond – Dementia Framework for Victoria* identifies priority actions for the short to medium term including:

- Supporting older people to live active and independent lives in their communities.
- Facilitating high quality health and aged care services to support people with dementia, and their families and carers.
- Encouraging creativity and innovation in flexible service delivery.
- Focusing on social connectedness, diversity and equity in meeting needs of people with dementia and their families and carers.

Throughout the State, Cognitive Dementia and Memory Services (CDAMS) provide specialist early diagnosis and assessment for people with dementia.

[www.health.vic.gov.au/agedcare/](http://www.health.vic.gov.au/agedcare/)

## Western Australia

The Western Australian *Dementia Action Plan 2003–2006* emphasises the following key action areas:

- Community awareness of the needs of people with dementia, their carers and families
- Community support strategies
- Early diagnosis and intervention
- The importance of acute care and primary care
- Education and training
- Research and policy development.

[www.health.wa.gov.au/publications/documents/Dementia\\_web.pdf](http://www.health.wa.gov.au/publications/documents/Dementia_web.pdf)