

## Dementia Action Plan 2007-2009

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**Summary** The plan summarises actions to be taken over the next two years with the following five Priorities for Action:

1. Diagnosis and Assessment, Care and Support Services that are flexible and can respond to the changing needs of people with dementia, carers and families.
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.
3. Information and education that is evidence-based, accurate and provided in a timely and meaningful way.
4. Research into prevention and delaying the onset of dementia as well as into the needs of people with dementia, their carers and families.
5. Workforce and training strategies that deliver skilled, high quality dementia care.

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# NSW Dementia Action Plan 2007–2009



**NSW HEALTH**



New South Wales  
Government



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October 2007

# NSW Dementia Action Plan 2007–2009

The NSW Government is committed to supporting people living with dementia, their carers and families.



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# Foreword

Early intervention is a concept that the NSW Government has embraced as a priority in the NSW State Plan for the planning and delivery of services over the next 10 years. For people with dementia, their carers and families, early intervention aims to reduce the impact of dementia and enable a person living with dementia to remain independent and to enjoy quality of life for as long as possible.

Early intervention includes access to early diagnosis, timely assessment and appropriate information and education. As needs increase, people with dementia, their carers and families benefit from good primary health care and flexible and responsive community support services provided by skilled staff. Early behavioural advice and intervention in the community can also prevent escalation of behavioural problems that can cause considerable distress and often lead to unnecessary admission to hospital.

If a person with dementia does need hospital care, the early detection of delirium, person centred care, involvement of carers and well-planned discharge enables a good patient journey. A palliative care approach in the final stages can provide comfort, reduce distress, and actively support and involve carers and families in the process.


The NSW Government is committed to supporting people living with dementia, their carers and families. The third NSW Dementia Action Plan builds on the achievements and lessons learnt from two previous NSW Dementia Action Plans and links to the opportunities that the *National Framework for Action on Dementia 2006–2010* offers NSW.

NSW Health has led the development of the third Dementia Action Plan and will deliver on the strategies in the plan in partnership with the Department of Ageing, Disability and Home Care (DADHC), and with service providers and key non-government organisations, such as Alzheimer's Australia NSW.

This document provides a summary of NSW actions over the next two years that will progress immediate priorities. The development of a Dementia Services Planning Framework as one of these priorities will guide NSW in the development of quality dementia services into the future.



**The Hon.  
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Minister for Health



**The Hon.  
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Minister for Ageing  
Minister for Disability Services

# Introduction

## Experiencing dementia

Dementia is an umbrella term for a variety of diseases that cause a progressive decline in memory, thinking capacity and judgment. The most common forms of dementia are Alzheimer's disease and vascular dementia. Some people may also develop dementia in relation to other disabilities or diseases such as Down Syndrome, Parkinson's Disease or HIV/AIDS.

Most dementias are not preventable or reversible, although healthy lifestyles may reduce risk and there are treatments that alleviate or delay symptoms for some people.

If a person reaches 80 years of age, they have about a one in 12 chance of developing some form of dementia. If they reach 85 years of age, the chance is nearly one in three. Although the primary risk factor for developing dementia is age, it is not a normal part of ageing.

Changes in the brain can also lead to changes in behaviour, emotional control or motivation. One third of people with dementia will experience moderate to severe behavioural and psychiatric symptoms.<sup>1</sup>

## Dementia in NSW

Dementia has assumed increasing prominence in policy and funding decisions in the last decade, mainly due to the ageing of the population.

In 2005, about 200,000 Australians (about one per cent of the population) had dementia. More than a third (about 71,000 people) lived in New South Wales.<sup>2</sup>

The incidence of dementia is increasing faster than earlier projections. Access Economics estimates that in 2050 there will be 730,000 people in Australia with dementia, about 227,000 people (31%) in New South Wales.

## Dementia policy, planning and service system

Most people with dementia live in the community supported by family, often spouses, and/or daughters and sons as well as friends and neighbours. The term "carer" is used to describe people who provide this additional care and support without payment other than in some cases a pension or benefit. Carers also need support in their caring role, as outlined in the NSW Carers Action Plan 2007–2012.<sup>3</sup>

Care and support for people with dementia and their carers is provided through a range of services and programs funded at a Commonwealth, State, regional and local level. There are dementia-specific services, such as outpatient memory clinics, dementia advisory services, dementia community nurses in Aged Care Assessment Teams (ACATs), dementia support groups, the National Dementia Helpline and the Living with Memory Loss programs through Alzheimer's Australia NSW.

The jointly funded Commonwealth and State Home and Community Care (HACC) Program provides mainstream services such as in-home respite as well as dementia-specific services such as dementia monitoring services and dementia-specific centre based day care. The National Respite for Carers Program (NRCP) provides both mainstream and dementia-specific respite and the national Extended Aged Care at Home (EACH) Program that provides high level home support also has a specific program for people with dementia and behavioural problems.

People with dementia, their families and carers can also access a wide range of mainstream support provided through programs such as the NSW Carers Program, Community Aged Care Packages (CACP), and the National Carers Counselling Program.

<sup>1</sup> Brodaty, H., Draper, B. & Low, L., 'Behavioural and psychological symptoms of dementia: a seven tiered model of service delivery' *Medical Journal of Australia*, 2003, 178 pp 231–234.

<sup>2</sup> Access Economics 2005 *Dementia estimates and projections, NSW and its regions*. Report for Alzheimer's Australia and NSW Health.

<sup>3</sup> NSW Department of Health 2007 *NSW Carers Action Plan 2007–2012*.

There have been considerable improvements in dementia care and support in NSW, including increased knowledge and awareness in the community and the health and aged care workforce, collaborative planning and more services on the ground. For example, funding for dementia-specific services under the HACC Program in 2006/07 included \$3.6 million for service expansion for people with dementia, building on a significant base of dementia-specific community services.

The last NSW dementia action plan, *Future Directions*<sup>4</sup>, added to the service infrastructure through the establishment of a network of 25 Dementia Advisory Services across the state and the creation of nine Dementia Clinical Nurse Consultant (CNC) positions allocated in six metropolitan and three rural Area Health Services.

The local planning and service development projects under *Future Directions*<sup>4</sup> promoted greater collaboration in dementia care and support, raised the profile of dementia and attracted additional funding regionally and locally. The plan also resulted in the development of a range of resources for dementia workers, people with dementia and their carers, including information and awareness resources for the public; education and training resources for acute health care workers, General Practitioners, HACC workers and public contact staff; guidelines for facility design and home modification; and assessment tools for General Practitioners and clinicians.

These achievements will be consolidated, promoted and shared in the implementation of this plan and through ongoing collaborative work with the Commonwealth Government and other States and Territories.

The dementia policy and funding environment has improved significantly with:

- the endorsement of the *National Framework for Action on Dementia 2006–2010* that provides a key joint policy document to coordinate efforts by governments across Australia; and
- the NSW rollout of \$3.95 million per annum enhancement funding in the 2005 NSW Budget and \$63.8 million new funding over five years from 2006/07 to support developments in community older people's mental health services and initiatives to improve mental health service responses to the needs of older people with severe behavioural and psychological symptoms of dementia (BPSD).

Given the increasing prevalence of dementia in the community it is vital that planning for the needs for people with dementia is incorporated into generic planning processes in the health and community care sectors with both Area Health Services and DADHC Regions taking responsibility for planning. This will include both planning for dementia-specific services and for improved responsiveness of mainstream services.

Feedback received in the development of the plan noted the vital importance of diagnosis and assessment in an early intervention approach and the need to enhance multidisciplinary diagnosis and assessment resources in the community as a priority.

Dementia policy overlaps with, and needs to be connected to, a range of policies and plans at different levels of government (Attachment A). Building linkages and increasing the integration of dementia in related policies and plans remains an ongoing focus.

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<sup>4</sup> NSW Department of Health 2002 *Future Directions for Dementia Care and Support in NSW 2001–2006*



# NSW Dementia Action Plan 2007–2009

NSW Health and DADHC will contribute to improving quality of life for people living with dementia, their carers and families through a commitment to the vision, outcomes and priorities for action outlined below.

The outcomes, prerequisites for success and priorities for action were developed in response to issues raised in reviewing the previous NSW Dementia Action Plan and the national direction provided through the National Framework for Action on Dementia.

Under each priority for action, the plan describes the strategies NSW Health and DADHC are committed to implementing in the next two years that will assist in achieving the outcomes sought for people living with dementia, their carers and families.

## Vision

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

## Outcomes

### For people and communities

- The impact of dementia is reduced or postponed.

### For service design, delivery and availability

- People with dementia receive timely and appropriate assessment.
- People with dementia and their carers obtain the information and assistance they need to make informed choices and decisions.
- People with dementia and their carers receive equitable access to timely, appropriate and coordinated services.
- All health and support systems and workers respond to people with dementia and their carers appropriately and effectively.

- Health and support systems and services for people with dementia and their carers are more cost effective.
- There is a commitment to researching innovative approaches.

## Prerequisites for success

- Collaboration and community involvement are fundamental to government policy and service delivery.
- There is agreement about service models and standards for dementia care.
- There is reliable data and evidence about what is in place, what works and what is needed.
- There is broad, practical community understanding of the nature of dementia and its impact on individuals and communities.

## Priorities for Action

- **Priority Area 1:** Diagnosis and Assessment, 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.



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

**Strategies 2007–2009**

**Lead agency**

**1. Service Planning**

- a) Develop a Dementia Services Planning Framework (DSPF), in consultation with Area Health Services and DADHC Regions that:
  - i) identifies the service mix and staffing levels that are reasonable to expect across NSW;
  - ii) acknowledges the importance of multidisciplinary diagnostic and assessment services in early intervention;
  - iii) identifies mechanisms for improved coordination of dementia service planning and delivery; and
  - iv) develops performance indicators for Area Health Services and DADHC Regions.

The Framework will be incorporated into Area Health Service and DADHC regional HACC planning processes and be used to support funding submissions where opportunities arise.

NSW Health  
in partnership  
with DADHC

- b) Lead the development of national delirium care pathways, following the release of the National Delirium Clinical Guidelines.

NSW Health

**2. Primary Health**

- a) Increase the number of community dementia nursing positions to assist in early diagnosis and accurate assessment of people with dementia and in linking people and their carers to timely support.

NSW Health

- b) Finalise previous NSW work of the GP Dementia Working Group and promote initiatives from the Primary Dementia Care Networks, Area Health Services and Dementia Advisory Services that assist primary health care professionals in the diagnosis and management of dementia and the support of carers.

NSW Health

**3. Dementia Screening and Assessment Tools**

- a) Share and promote at a state and national level previous NSW work regarding dementia screening for people with intellectual disabilities.

DADHC

- b) Develop programs involving joint assessment of older people with intellectual disability who are showing a change in behaviour that suggests possible dementia.

DADHC

**4. Community Care**

- a) Increase and improve dementia-specific HACC services, such as centre-based day care.
- b) Continue to fund Dementia Advisory Services and support the Professional Dementia Network.
- c) Continue to grow local community dementia services within available HACC growth funds.

DADHC

DADHC

DADHC

**5. Acute Care**

- a) Review the Dementia CNC positions with a view to funding recurrently, providing consistent direction and strengthening their network.

NSW Health

**6. Palliative Care**

- a) Strengthen links between dementia services and the NSW Palliative Care Program.

NSW Health



## Strategies 2007–2009

## Lead agency

### 7. Behavioural Issues

- a) In partnership with Mental Health and Aged Care sectors continue to implement the 'severely and persistently challenging behaviours' model outlined in the *NSW Service Plan for Specialist Mental Health Services for Older People*<sup>5</sup> to respond to the needs of people with severe and persistent behavioural and/or psychiatric symptoms associated with dementia. The model incorporates Behavioural Assessment and Intervention Services (BASIS) and transitional assessment and treatment facilities in inpatient and residential aged care settings.<sup>6</sup>
- b) Identify features of a HACC service model or models to meet the needs of people with dementia and challenging behaviours.

NSW Health

DADHC

**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.

### 1. Barriers to Access

- a) Review information on barriers to access identified in the Dementia Planning and Service Development Projects.
- b) Address barriers of access, particularly for people in rural and remote areas in the Dementia Services Planning Framework through building on existing models such as Telehealth services.

DADHC

NSW Health  
in partnership  
with DADHC

### 2. People from Culturally and Linguistically Diverse (CALD) Backgrounds

- a) Develop a community based approach to addressing the needs of people with dementia in CALD communities.
- b) Review and extend the model if appropriate and when funding opportunities arise.
- c) Assess the need for further dementia awareness training for health care interpreters.

DADHC

DADHC

NSW Health

### 3. Younger Onset Dementia

- a) Identify features of a HACC service model or models to meet the needs of people with a younger onset of dementia, incorporating more flexible service provision and addressing gender specific services.
- b) Review the pilot of the Younger Onset Dementia Training Package and develop an appropriate implementation plan for the sector.

DADHC

DADHC

### 4. Aboriginal and Torres Strait Islander People

- a) Implement the National Dementia Learning Resource for Aboriginal and Torres Strait Islander Communities both for Aboriginal carers (Part 1) and for Aboriginal health and community care workers (Part 2&3).
- b) Develop a community based approach to addressing the needs of Aboriginal and Torres Strait Islander people with dementia.

DADHC in  
partnership  
with NSW  
Health

DADHC

<sup>5</sup> [http://www.health.nsw.gov.au/policies/gl/2006/pdf/GL2006\\_013.pdf](http://www.health.nsw.gov.au/policies/gl/2006/pdf/GL2006_013.pdf).

<sup>6</sup> The model draws on the NSW Health *Summary Report: The Management and Accommodation of Older People with Severely and Persistently Challenging Behaviours* ([http://www.health.nsw.gov.au/pubs/2006/summary\\_aged\\_diff.html](http://www.health.nsw.gov.au/pubs/2006/summary_aged_diff.html)).



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

**Strategies 2007–2009**

**Lead agency**

a) Complete Planning Ahead projects for HACC clients from CALD and Aboriginal communities.	DADHC
b) Release and promote the Interagency Protocol for Responding to Abuse of Older People.	DADHC in partnership with NSW Health
c) Develop protocols for ACATs and other relevant health workers to respond to complex situations of abuse.	NSW Health
d) Develop a training model to build advance care planning expertise in targeted health professional groups.	NSW Health
e) Continue to support and fund Dementia Awareness Week and other community awareness activities.	DADHC
f) Support evidence based education strategies to reduce risk factors and promote healthy ageing.	NSW Health

**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.

a) Promote awareness of research outcomes through sponsorship of dementia conferences and workshops and partnerships with existing research centres.	NSW Health DADHC
b) Continue to negotiate access to HACC research funds for research into dementia service models.	DADHC

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

a) Support training of health workers in high quality dementia care that complements other recent training initiatives under Dementia as a National Health Priority such as the Eastern Australia Dementia Training Study Centre, based at the University of Wollongong.	NSW Health
b) Work with the Workforce Development and Leadership Branch, NSW Health to identify, promote, and address dementia related workforce issues, including workforce issues in rural and remote areas. This includes developing strategies to address medical workforce shortages around dementia diagnosis and management.	NSW Health
c) Identify dementia related workforce issues in the community care sector, and examine ways to address these issues through the HACC Learning and Development Framework and other industry development initiatives in DADHC.	DADHC

# Governance and reporting

NSW Health is the lead agency for the third NSW Dementia Action Plan, working in close collaboration with DADHC at a State and Area Health Service/ DADHC regional level.

NSW Health and DADHC will use the existing reporting mechanisms to monitor the implementation of the third dementia plan through regular reporting to the following:

- The DADHC/NSW Health Senior Officers Group that reports to the bi-monthly DADHC/NSW Health Director General meetings;
- The Chronic, Aged and Community Health Health Priority Taskforce [CACH HPT] that has membership from the health and community sectors and reports to the Health Care Advisory Council; and
- Annual business and HACC reporting mechanisms.

# Performance indicators and evaluation

An evaluation strategy for the third state plan will be developed as a priority. This will include:

- The development of performance indicators for the plan as a whole and service performance indicators for NSW Health and DADHC developed under the Dementia Services Planning Framework;
- Mechanisms for consistent regular reporting against these performance indicators that can be incorporated into existing NSW Health and DADHC reporting requirements; and
- Linkage to the proposed national evaluation of the National Framework for Action on Dementia.

# Attachment A

## Related National and NSW Policy Frameworks

### National

- *Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004–2009*
- *The National Palliative Care Strategy 2000*
- *A New Strategy for Community Care — The Way Forward (Community Care Review) 2002–2007*
- *From Hospital to Home: Improving Care Outcomes for Older People. National Plan for Improving the Care of Older People Across the Acute Care Continuum 2004–2008*
- *National Health Workforce Strategic Framework 2004*
- *National Mental Health Plan 2003–2008*

### NSW

- *NSW State Plan*
- *NSW State Health Plan*
- *NSW Carers Action Plan 2007–2012*
- *NSW Health Workforce Action Plan*
- *Two Ways Together: the NSW Aboriginal Affairs Plan 2003–2012*
- *Aboriginal Workforce Development Strategic Plan 2003–2007*
- *NSW Health Palliative Care Framework: A Guide for the Provision of Palliative Care in NSW 2001–2004.*
- *Integrating Primary and Community Health Policy 2007–2012*
- *NSW: A New Direction for Mental Health 2006*
- *NSW Interagency Action Plan for Better Mental Health*
- *NSW Health NSW Community Mental Health Strategy*
- *NSW Service Plan for Specialist Mental Health Services for Older People*
- *NSW Health Summary Report: The Management and Accommodation of Older People with Severely and Persistently Challenging Behaviours*
- *Stronger Together: A new direction for disability services in NSW 2006–2016*
- *Better Together: A new direction to make NSW Government services work better for people with a disability and their families 2007–2011*
- *Framework for integrated support and management of older people in the health care system 2004–2006*



