**Dementia Services Framework 2010-2015**

**Summary** The Framework is for health, community and residential services to assist with planning and development of dementia services and programs. It reviews service needs and makes recommendations along a service pathway of dementia care from awareness through diagnosis, assessment, community, hospital and residential care. Recommendations are practical and aim to improve access, diagnosis and continuing care. It can be used as a checklist for reviewing the way services are currently provided and can encourage reflection on how services could be delivered differently to improve outcomes for people with dementia, carers and families.

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NSW DEMENTIA SERVICES FRAMEWORK 2010-2015

PURPOSE

The *NSW Dementia Services Framework 2010-2015* is a joint publication of the NSW Department of Health and NSW Department Ageing, Disability and Home Care that sets the direction for improving quality of life for people with dementia, their carers and families in NSW. It is underpinned by the following principles that emphasise quality dementia care is contingent on being responsive to the needs and experiences of people with dementia, their carers and families.

KEY PRINCIPLES

1) All people with dementia have access to competent and timely, multidisciplinary assessment, diagnosis, care management and support services.
2) People with dementia are valued and respected. Their right to dignity and quality of life is supported.
3) Carers and families are valued and supported. Carers are able to exercise choice in their role as a carer.
4) People with dementia, carers and families are central to making choices about care.
5) Services recognise that individuals vary in their symptoms, rates of progression and needs. Service responses should consider the person, the family and the context as well as the immediate concern irrespective of the service being provided.
6) All people with dementia, carers and families receive care and support that is sensitive to social, cultural or economic background, location and need.
7) A well-trained and supported workforce delivers quality dementia care.
8) Communities play an important role in quality of life for people with dementia, their carers and families.

USE OF THE GUIDELINE

The Framework is for services in health, community and residential care settings to assist with planning and development of dementia services and programs. It reviews service needs and makes recommendations along a dementia care service pathway from awareness through diagnosis, assessment, community, hospital and residential care.

Recommendations are practical and aim to improve access, diagnosis and continuing care.

It can be used as a checklist for reviewing the way services are currently provided and can encourage reflection on how services could be delivered differently to improve outcomes for people with dementia, carers and families.

A NSW implementation plan will be developed to provide further direction for action that aligns with NSW Health responsibilities.

REVISION HISTORY

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ATTACHMENTS

1. NSW Dementia Services Framework 2010-2015
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In late 2009 the NSW Government embarked on the task of developing the NSW Dementia Services Framework in order to set the direction for NSW in providing quality dementia care, within the context of a rapidly ageing population.

Through input of an expert advisory group, consultation with NSW dementia services networks and Alzheimer’s NSW regional consumer committees and through a review of relevant reports and research articles, the NSW Dementia Policy Team has identified current issues and challenges along the service pathway from dementia awareness to palliative care, outcomes for people with dementia, carers and families into the future and the service elements required along the service pathway to achieve these outcomes.

Quality dementia care relies on services from current health, community care and aged care systems that are mainstream and dementia specific and also on how well these systems interact. Australia’s health system is about to undergo considerable reform through the Council of Australian Governments (COAG) National Health and Hospitals Network Agreement with the objective of improving health outcomes and the sustainability of the Australian health system. At the same time the Commonwealth is taking over policy and funding responsibility of aged care to create a more unified and consistent aged care system. These reforms have the potential to substantially improve outcomes for people with dementia, carers and families. These outcomes should include earlier diagnosis, better access to services, geographical consistency in service quality and provision, better carer support and greater opportunities to remain at home.

Many administrative, program and policy decisions will be made by the Commonwealth Government in partnership with States and Territories over the next few years in the move to the Medicare Locals, Local Hospital Networks and One Stop Shops in aged care. This Framework can assist in providing direction for quality dementia care under these new arrangements. The key outcomes sought and the service elements required are likely to stay constant while the responsibilities for implementing recommendations will change as the health and aged care reforms come into effect.

The NSW Government is committed to this Framework and to working with the Commonwealth to improve outcomes for people with dementia, carers and families.

The Hon. Carmel Tebbutt MP
Deputy Premier
Minister for Health

The Hon. Peter Primrose MP
Minister for Ageing
# Acronyms

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<td>AA</td>
<td>Alzheimer’s Australia</td>
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<td>AARCS</td>
<td>Acute to Age Related Care Services</td>
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<td>ABDQ</td>
<td>Adaptive Behaviour Dementia Questionnaire</td>
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<td>ACAT</td>
<td>Aged Care Assessment Team</td>
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<td>ACP</td>
<td>Advance Care Planning</td>
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<td>ADAHPS</td>
<td>AIDS Dementia &amp; HIV Psychiatry Service</td>
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<td>ADC</td>
<td>AIDS Dementia Complex</td>
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<td>ADHC</td>
<td>Ageing, Disability and Home Care</td>
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<td>AHMC</td>
<td>Australian Health Ministers’ Conference</td>
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<td>AHS</td>
<td>Area Health Service</td>
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<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
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<td>ANU</td>
<td>Australian National University</td>
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<td>AMS</td>
<td>Aboriginal Medical Service</td>
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<td>ASET</td>
<td>Aged Care Services in Emergency Team</td>
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<td>ASLaRC</td>
<td>Aged Services Learning and Research Collaboration</td>
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<td>BASIS</td>
<td>Behavioural Assessment and Intervention Service</td>
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<td>BCS</td>
<td>Baptist Community Services</td>
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<td>BPSD</td>
<td>Behavioural and Psychological Symptoms of Dementia</td>
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<td>CAPAC</td>
<td>Community Acute Post-Acute Care</td>
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<td>CALD</td>
<td>Culturally and Linguistically Diverse</td>
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<td>HACC</td>
<td>Home and Community Care</td>
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<td>HAND</td>
<td>HIV Associated Neurocognitive Disorder</td>
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<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<td>HITH</td>
<td>Hospital in the Home</td>
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<td>Hornsby Ku-ring-gai Hospital Service</td>
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<td>LWML</td>
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<td>NFAD</td>
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<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
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<td>NICE</td>
<td>National Institute for Clinical Excellence</td>
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<td>NP</td>
<td>Nurse Practitioner</td>
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<td>OFA</td>
<td>Office For Ageing</td>
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<td>OPERA</td>
<td>Older Person's Evaluation Review and Assessment</td>
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<td>PLAC</td>
<td>Positive Living in Aged Care</td>
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<td>Power of Attorney</td>
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<td>POWH</td>
<td>Prince of Wales Hospital</td>
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<td>QUT</td>
<td>Queensland University of Technology</td>
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<td>Abbreviation</td>
<td>Full Form</td>
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<tr>
<td>RACF</td>
<td>Residential Aged Care Facility</td>
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<td>RACGP</td>
<td>Royal Australian College of General Practice</td>
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<td>RUDAS</td>
<td>Rowland Universal Dementia Assessment Scale</td>
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<td>SCDMP</td>
<td>Severe Chronic Disease Management Program</td>
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<td>T-BASIS</td>
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<td>UK</td>
<td>United Kingdom</td>
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<td>YOD</td>
<td>Younger Onset Dementia</td>
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Vision

The NSW Dementia Services Framework 2010-2015 sets the direction for improving quality of life for people with dementia, carers and families in NSW. It is underpinned by the following principles that emphasise quality dementia care is contingent on being responsive to the needs and experiences of people with dementia, carers and families.

Principles

1. All people with dementia have access to competent and timely, multidisciplinary assessment, diagnosis, care management and support services.
2. People with dementia are valued and respected. Their right to dignity and quality of life is supported.
3. Carers and families are valued and supported. Carers are able to exercise choice in their role as a carer.
4. People with dementia, carers and families are central to making choices about care.
5. Services recognise that individuals vary in their symptoms, rates of progression and needs. Service responses should consider the person, the family and the context as well as the immediate concern irrespective of the service being provided.
6. All people with dementia, carers and families receive care and support that is sensitive to social, cultural or economic background, location and need.
7. A well-trained and supported workforce delivers quality dementia care.
8. Communities play an important role in quality of life for people with dementia, carers and families.

Actions

1. Improve community awareness about dementia, available help and the link between healthy lifestyles and reduced dementia risk.
2. Improve access to timely dementia assessment, diagnosis and management services.
3. Improve access to information, counselling, carer education and support.
4. Improve the availability and flexibility of community support programs and services.
5. Improve the quality of and expertise for dementia care in hospitals.
6. Improve the quality of and expertise for dementia care in residential aged care settings.
7. Improve access to quality care and expertise for the assessment and management of behavioural and psychological symptoms of dementia.
8. Improve access to quality care and expertise for palliative dementia care.

Enablers

1. Improve structures that support funding, planning and policy directions for quality dementia care.
2. Improve workforce development and training for quality dementia care.
3. Improve the evidence base and use of service data to inform the provision of quality dementia care.

Implementation

Quality dementia care consists of integrated Commonwealth, NSW and jointly funded services and programs across health (primary, aged health, mental health), community, aged and residential care. Actions included within the Framework span across both national and state areas of responsibility. Its implementation requires the commitment of multiple stakeholders to work in partnership to improve the experience of people with dementia, carers and families. The next stage for NSW will be the selection of recommendations that align with state responsibilities and the development of an implementation plan.
Dementia is an umbrella term for a variety of diseases that cause a decline in multiple areas of cognition such as in memory, judgment, communication and a decline in abilities to carry out activities of daily living.

It is one of the fastest growing sources of major disease burden, now being the third leading cause of death, after heart disease and stroke. The number of people with dementia in NSW is projected to increase fourfold from 84,000 in 2009 to 341,000 in 2050 and corresponds with the diagnosis of near 26,000 new cases annually in NSW increasing to 116,000 new cases in 2050.

Consequently, dementia is a significant financial challenge, with a projected change in health and residential aged care national expenditure of $14 billion from 2003 to 2033, $3.8 billion in 2003 to $17.8 billion in 2033.

Dementia is also a significant health challenge. It is a serious chronic, usually progressive condition, often with complex physical co-morbidities as well as psychological and behavioural symptoms, requiring expert clinical assessment, diagnosis and management. Dementia demands considerable time, effort and resources to ensure the provision of quality care.

Older people fear it more than any other health condition. People with dementia can feel they are no longer valued. Care is mostly provided by carers and family members who can become physically and emotionally overwhelmed and socially isolated for extended periods.

There are, however, examples internationally and locally of people being able to "live well" with dementia, with continued meaning, enjoyment and a good quality of life, of good health care and of carers being well supported. In this context, caring for someone with dementia can be a positive experience. Care provision needs to be focused holistically on the person with dementia and their carer at all points in the progression of the condition and regardless of setting. It needs to account not only for their physical well-being but also account for psychological, emotional, social and cultural experience. Maintenance of carers’ health and well being is crucial.

The prior implementation of three NSW dementia plans including the NSW Action Plan on Dementia 1996-2001, Future Directions for Dementia Care and Support 2001-2006, and the NSW Dementia Action Plan 2007-2009, as well as NSW Health’s leading the development of the National Framework for Action on Dementia 2006-2010 is evidence of the NSW Government’s commitment to responding to the challenges and impact of dementia.

Feedback on the experience of dementia care from consultations held with dementia service providers and carers across NSW during 2010 has confirmed that there are significant issues that still need to be addressed to improve the quality of life for people with dementia, carers and families.

Issues most commonly reported in the consultations were:

- The enormous impact of providing dementia care on carers and families versus the limited capacity of health and community care services to respond to the needs for additional support;
- The additional impact of behavioural and psychological symptoms of dementia (BPSD) in reducing care choices;
- Lack of and delay in diagnosis, resulting in missed opportunities to plan ahead for care requirements and the subsequent late presentation to services, often in crisis;
- Overwhelming demand on the existing, limited workforce with dementia expertise and on dementia specific services in providing care and support;
- Geographic variability in people having access to services and in how well the service system can be navigated, how well services work together and how flexible they are; and
- Poor experiences for people with dementia in hospitals, multipurpose services and residential care facilities.
The challenge in response to such issues is to find solutions within the context of the significant, fourfold expected increase in dementia and potential improvements resulting from the implementation of the health and aged care reforms being implemented through the Council of Australian Governments (COAG) National Health and Hospitals Network Agreement that has the objective of improving health outcomes and the sustainability of the Australian health system.

Supporting people with dementia, carers and families requires a co-ordinated and planned approach across health services (primary care, aged care and mental health) and community care services that also takes account of the important interface with residential aged care. Funding and policy responsibility for health, community and residential services extends across both Commonwealth and NSW Governments, with considerable investment in supporting carers and the delivery of these services in collaboration with non-government organisations (NGOs).

The NSW Dementia Services Framework 2010-2015 sets the direction for providing quality dementia care in NSW. Developed through consultation with clinical and research experts, service providers, carers and consumers, it emphasises the needs and experiences of people living with dementia, as well as their carers. It further acknowledges that some people with dementia will not have access to a carer and require additional services in the absence of this support.

It addresses the needs and experiences of specific population groups in accessing quality dementia care. This includes people from culturally and linguistically diverse backgrounds (CALD), Aboriginal people, people living in rural and remote communities, people with younger onset dementia (YOD), people with intellectual disability, who identify as either gay men, lesbian, bisexual, transgender or intersex (GLBTI), or in correctional centres.

The Framework presents dementia care as a journey that occurs along a service pathway, commencing at dementia awareness and proceeding through several stages requiring different types of care and support at each stage up until end of life care provision. Stages include access to assessment, diagnosis and ongoing clinical management, as well as information, counselling and carer education following a diagnosis being made. They also include access to care and support across community, hospital and residential care settings, sometimes requiring specialist interventions for behavioural and psychological symptoms of dementia and/or palliative care.

It also recognises that across the service pathway there are key enablers that are not specific to any stage of care but critical to the establishment of service infrastructure necessary for sustained provision of quality dementia care (see Figure 1). This includes a commitment of funding, service planning and coordination, training and workforce development, and strengthening evidence for quality dementia care.
Priorities

Priorities for the service pathway include:

- Creating greater community awareness of dementia that reduces stigma;
- Strengthening access to skilled dementia health experts to improve assessment, diagnosis and management;
- Providing a key worker to support people with dementia, carers and families to enable continuity of care over the “long haul”;
- Expanding access to support services and flexible packaged care;
- Recognising and appropriately responding to delirium and dementia in hospitals;
- Increasing the availability of staff trained to assess BPSD in the community, hospitals and residential aged care facilities (RACF);
- Establishing designated acute behavioural units for people with delirium/dementia and behavioural difficulties;
- Establishing sub acute/non-acute transitional assessment and treatment units for severe BPSD in each Area and specialist intensive care units for very severe BPSD for NSW;
- Encouraging advance care planning; and
- Increasing access to palliative care for people with advanced dementia, including access to specialist palliative care services, when required.
Priorities for the enablers include:

- Developing a dementia care population planning model;
- Undertaking integrated dementia planning and service coordination at a network level, including rural areas;
- Increasing dementia training opportunities across primary, community, hospital and residential care sectors; and
- Planning for expected workforce demand.

For each stage of the pathway outlined in the Framework, key requirements are specified to achieve outcomes for quality dementia care to meet the needs of people with dementia, carers and families. Actions for improvement of existing services and programs are also specified to align with the key returns on requirements (Appendix 1).

Importantly, the crucial mix for good dementia care consists of integrated Commonwealth, NSW and jointly funded services and programs. Therefore, actions included within the Framework span across both national and state areas of responsibility.

Principles

The Framework is underpinned by the NFAD principles that emphasise quality dementia care is contingent on being responsive to the needs and experiences of people with dementia, carers and families.15 The principles for the Framework are:

1. All people with dementia have access to competent and timely, multidisciplinary assessment, diagnosis, care management and support services.
2. People with dementia are valued and respected. Their right to dignity and quality of life is supported.
3. Carers and families are valued and supported. Carers are able to exercise choice in their role as a carer.
4. People with dementia, carers and families are central to making choices about care.
5. Services recognise that individuals vary in their symptoms, rates of progression and needs. Service responses should consider the person, the family and the context as well as the immediate concern, irrespective of the service being provided.
6. All people with dementia, carers and families receive care and support that is sensitive to social, cultural or economic background, location and need.
7. A well-trained and supported workforce delivers quality dementia care.
8. Communities play an important role in quality of life for people with dementia, carers and families.

Implementation

The Framework aims to set the direction for developing quality dementia care by answering the questions: What are we aiming to do and why? It is a tool for service planning and development and informs both Commonwealth and NSW Government funding, policy and planning decisions. It can be used as a checklist for reviewing the way services are currently provided and can encourage reflection on how services could be delivered differently to improve outcomes for people with dementia, carers and families. The recommendations are not confined to NSW agencies alone and may be progressed through funding, service redesign or other opportunities that arise at a state and national level and through the commitment of multiple stakeholders to work in partnership.

The next stage for NSW will be the selection of recommendations that align with state responsibilities and the development of an implementation plan. NSW will also work with the Commonwealth in areas of their responsibility to strengthen integration consistent with the COAG reforms.

The implementation plan will be developed for release in 2011 to address the following:

- How will we do it?
- Who will do it?
- When will it be done?
- How will we know it has been done?
- What will it cost?

The NSW Government is committed to improving the quality of life of people living with dementia, carers and families.
Definition

Dementia is an umbrella term for a variety of diseases that cause a progressive decline in multiple areas such as memory, judgment, communication and ability to carry out activities of daily living. The most common forms of dementia are Alzheimer’s disease and vascular dementia or a mixture of both. Other forms of dementia include dementia with Lewy bodies and frontotemporal dementia, previously known as Pick’s disease. People may also develop dementia in other conditions such as Parkinson’s disease, Huntington’s disease, Down syndrome and HIV/AIDS.

Accurate diagnosis is important as symptoms, prognosis and treatment vary with the type of dementia.

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. Although the primary risk factor for developing dementia is age, it is not a normal part of ageing. It is uncommon under the age of 60, but it can appear in people aged in their 40s or younger.

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.

Dementia is a serious chronic condition, often with complex physical co-morbidities and increased risk of delirium.

Impact

The attitudes and support of family and friends and of the wider community impacts on the adjustment to a diagnosis of dementia.

While there is increasing awareness of dementia, it is also feared, accompanied by stigma and the negative perception that nothing can be done. Often people with dementia are avoided or treated differently and relatives and friends feel awkward and do not know how to react, leaving the family feeling isolated.

However, with the right support and attitude people with dementia can continue to enjoy life. One of the most important advances in the dementia field is that the experiences of people themselves are now communicated and people with dementia are more involved in research and service development. A recent study in UK, My Name is not Dementia, found that maintaining a good quality of life was possible following a diagnosis, and that the factors outside the person’s dementia (including people with severe dementia assessed through the use of picture cards) were relevant to quality of life among people with dementia. This included relationships, environment, physical health and sense of humour.16

As care needs increase, the impact on family members who provide care can be overwhelming, particularly if the person with dementia is experiencing BPSD. There is increasing evidence that early multi component interventions can make a difference.

Carers

The majority of people with dementia in the community, particularly those with increased dependency, have a carer.10 The vast majority of care is provided by family and friends usually termed “carers”, (or “caregivers”) who provide emotional support, practical assistance and supervision through to assistance with personal care for extended periods.10

While caring can be a positive experience its negative impact on carers’ physical health and emotional wellbeing and financial security has been extensively researched.17 Carers of people with dementia in particular have high levels of psychological morbidity and social isolation.11
More research is needed to ascertain the most effective interventions for carers of people with dementia at specific stages of their caring journey. *The Carers Life Course Framework* developed by Carers NSW provides a potential guide.18

It is likely that the numbers of carers will increase but not as fast as those needing care and there is likely to be more working carers. The caring role needs to be more sustainable through increased recognition and support.

**People without Carers**

Not all people with dementia have carers with whom they live or have close contact. The number of people living on their own will increase due to the ageing of the population, increase in divorce and separation and delay in marriage.19 People with dementia living alone without carers are at increased risk of adverse outcomes such as social isolation, exploitation, and self neglect including poor nutrition. However, services can be provided in a way that minimises risks and enables them to remain at home longer.

**Prevalence Projections**

By 2036, older people (people aged 65 years and over) are expected to represent 21.5 percent of the NSW population, up from 13.5 percent in 2006.20 Every Statistical Local Area (SLA) in NSW is projected to experience population growth among people aged 65 years and over.20

Dementia is one of the fastest growing sources of major disease burden, recently overtaking lung diseases. It is now the third leading cause of death, after heart disease and stroke.8 Access Economics has projected that the number of people with dementia in NSW will increase fourfold from 84,000 in 2009 to 341,000 in 20509 (see Figure 2).

![Figure 2. Projected prevalence of dementia in NSW by gender, 2010-2050.](source: Access Economics 2009)
This corresponds with a projected annual incidence rate of near 26,000 new cases in 2010 that will increase to 116,000 new cases in 2050 (see Figure 3).

In 2009 the Area Health Service (AHS) with the highest number of people with dementia was North Sydney/Central Coast AHS with around 16,400 people. By 2050 the AHS region with the highest number of people with dementia is estimated to be Sydney South West AHS, with around 60,000. Ageing, Disability and Home Care’s Metropolitan South region will remain the highest region, increasing from 23,100 to around 95,000; their having recently conducted a large dementia needs analysis in response.

The projected increase in dementia poses a serious planning challenge in meeting demand for the range of health, community care and aged care services such as assessment and diagnostic services when current access is limited. Models of care need to be developed that provide effective intervention in a resource efficient manner.

Figure 3. Projected incidence of dementia in NSW by gender, 2010-2050. 

Source: Access Economics 2009
Access Economics has estimated that, in the absence of any policy changes, Australia will experience a shortage of over 58,000 full-time equivalent (FTE) paid dementia care staff (70 percent of current workforce) and a shortage of 94,266 FTE family carers (80 percent of current family carers) by 2029.21

**Specific Population Groups**

Individuals respond to dementia in different ways. There is also diversity in perception and understanding of dementia across cultures. The term dementia is meaningless in some communities and perceived as a normal part of ageing in others. There are also beliefs that dementia is related to mental illness, with an extreme of this being the perception that dementia is a form of ‘craziness’.22 While the term “specific population groups” is used in this document to consolidate information in capturing the breadth of diversity, it is acknowledged that specific population groups have distinctly different dementia care needs and requirements.

**Culturally and Linguistically Diverse Communities (CALD)**

In 2005 it was estimated that of all NSW residents with dementia, there were 12.9 percent, almost 1 in 8 people, who did not speak English at home.23 Importantly, the proportion of older people from CALD backgrounds in NSW is projected to grow from 18 percent in 1996, to 23 percent of the total older population by 2026. Concurrently, the proportion of people 80 years and over from CALD backgrounds is projected to grow from 13 percent to 25 percent of the population over the same period. This indicates that there will be an increasing need for access to dementia care services by people from CALD backgrounds.24

Even when people from CALD backgrounds are fluent in English, once they develop dementia and start having difficulties with language it is generally the most recently acquired language that is lost first among people with dementia. Sometimes a mix of native and second languages is used for a time, presenting challenges for interpreter services.2

There is also evidence that people from some non-English speaking backgrounds may present later to services such as memory clinics, even if there is a bilingual specialist available.22

**Aboriginal People**

NSW has the largest number of Aboriginal people per state and territory in Australia. Around 148,178 Aboriginal people live in NSW, comprising just over 2 percent of the NSW population and 29 percent of the total Australian Aboriginal population.25 The Aboriginal population is younger than the non-Aboriginal population, with the proportion of Aboriginal people over the age of 65 years being just over 3 percent compared with just over 13 percent for the non-Aboriginal population.25

Aboriginal people in NSW predominately reside in urban and regional areas of NSW though they comprise the largest proportion of the population in the most remote regions of NSW.26 Among NSW AHS regions, the Hunter & New England AHS region had the largest Aboriginal population (22.2 percent of the total NSW Aboriginal population), followed by the Greater Western AHS region (17.3 percent). At the Local Government Area (LGA) level the largest number of Aboriginal people resides in the Blacktown LGA (7,600). The population proportion of Aboriginal people ranges from 0.1 percent in the Mosman LGA, Willoughby LGA and Ku-ring-gai LGA to 62.7 percent in the Brewarrina LGA.25

Aboriginal people continue to make up an increasing proportion of the population with increasing remoteness, and comprise 32 percent of the population of very remote areas. However, it is important to also note that only 5.6 percent of Aboriginal people in NSW live in ‘remote’ or very remote areas and that 51 percent live in metropolitan Sydney.25

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42 percent of Aboriginal people in NSW identify with a particular clan, tribal or language group (see Figure 4), but only about 800 Aboriginal people speak an Aboriginal language.26

Aboriginal people remain significantly disadvantaged on a range of priority indicators such as health, education, economic development, justice, housing and infrastructure when compared with non-Aboriginal people.27 Measures include shorter life expectancy by more than 16 years, greater infant mortality, higher hospitalisation for long term chronic conditions such as diabetes and cardiovascular disease, half as likely to complete year 12 from year 10, higher learning disorders secondary to lack of parenting, high rates of attention deficit hyperactivity disorders (ADHD), higher unemployment, high psychological distress and use of mental health services, over representation of Aboriginal women as victims of sexual assault and domestic violence related assault, 80 percent higher rate of personal violence against Aboriginal males than the general male population, significant higher criminal court appearance and incarceration and high rates of homelessness, with overcrowding in social housing, therefore, contributing to a higher level of environmental health issues.26

The poor health status of Aboriginal people is well documented with high rates of chronic disease due to a combination of social and environmental circumstances (see Appendix 2) and increased risk behaviours, such as smoking, physical inactivity, poor diet and risky consumption. Aboriginal people are less likely to drink alcohol than people in the non Aboriginal population. However, for those who do drink, a higher proportion drink at risky or high risk levels.28

The reasons for poor Aboriginal health status are complex. As well as socioeconomic disadvantage, the impact of colonisation and the subsequent the loss of economic, spiritual and cultural base may provide an explanation.28

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*a* NSW Health Disclaimer: This map indicates only the general location of large groupings of people, which may include smaller groups such as clans, dialects, or individual languages in a group. The boundaries are not intended to be exact. This map is not suitable for use in native title or other land claims.
Aboriginal People and Dementia

It is known that the dementia prevalence amongst remote Aboriginal communities is substantially higher than in the non-Aboriginal population. The Kimberley Indigenous Cognitive Assessment (KICA) study in Western Australia found prevalence of 12.4 percent for Aboriginal people, substantially higher than 2.4 percent for the overall Australian population over 45 years of age. However, these comparisons should be viewed with caution as numbers were small and confidence intervals wide.

It is not yet known if prevalence is also higher in urban areas. A prevalence study of urban communities is underway in NSW, called the Koori Growing Old Well Study (KGOWS), located at Neuroscience Research Australia (NEURA) in Sydney. The study will assess over 600 people aged 60 years and over selected from collaborating urban and regional Aboriginal communities in NSW. These include La Perouse, Mt Druitt, Campbelltown, Nambucca, Kempsey and Coffs Harbour.

The social and health profile of Aboriginal people show many of the risks associated with a greater chance of developing dementia in later life. Higher prevalence is likely due to lower formal education, high levels of social trauma, more chronic disease, less opportunity for skill development (all leading to reduced cognitive reserve) and a high prevalence over the life-time of traumatic brain injury and drug and alcohol morbidity. Aboriginal people are surviving to mid life and reaching old age. Aboriginal communities are experiencing the health transition some forty years after the non-Aboriginal population. "Changes over the last decade with more people between 45 and 64 years, fewer people dying from chronic disease in some parts of the country suggest that Aboriginal populations are starting to age in a similar way to the rest of Australia." However, the life experiences of those Aboriginal people who are now adults and entering old age are likely to increase their risk of developing dementia.

Rural and Remote Communities

Older people in NSW aged 65 years and over live predominantly along the Eastern seaboard or clustered around larger regional centres in inland NSW (eg Tamworth, Bathurst, Orange, Dubbo, Goulburn, Albury, Wagga Wagga).

By contrast, there is a scattering of older people living in or near smaller satellite towns and more remote communities. These remote regions of NSW are largely typified by a dispersed population over a large geographic area which contributes to difficulty in providing dementia care. This includes geographic isolation, socioeconomic disadvantage, shortage of health care providers, lower levels of access to health services, greater exposure to injury risks, and poorer health among Aboriginal people who comprise a significant proportion of the population in remote areas. Their isolation is compounded by the tendency of their children to migrate to the cities, leaving them without support.

An estimated 38,006 people (0.55 percent of the population) live in areas classified as remote or very remote NSW. This includes the regions of Bogan, Unincorporated NSW, Bourke, Central Darling, Brewarrina, Cobar, Walgett, Coonamble, Carrathool, Lachlan, Warren, Hay, Balranald and Moree Plains.

Estimates derived from Access Economics dementia prevalence data indicate that of 87,961 cases of dementia in NSW in 2010, 358 will be in remote and very remote areas. This will increase to 1,026 cases in 2050. Although these areas and towns in western NSW are not areas of high dementia incidence they are remote areas that are poorly serviced.
Younger Onset Dementia

While dementia is predominately a disorder related to old age, dementia can affect people under 65 years of age. The experience of symptom onset before the age of 65 years is referred to as younger onset dementia (YOD).

Access Economics indicates that the prevalence of dementia for persons under 60 years of age is rare, with prevalence increasing to 1.2 percent of males and 0.6 percent of females aged between 60 and 64 years of age. A recent prevalence study in the northern sector of South Eastern Sydney and Illawarra Area Health Service found a much higher rate of 1 in 750 people aged 45 to 64 years of age.

YOD comes in many forms. Alzheimer’s disease is the most common form of dementia but is less common among people under 65 years of age when compared with the rates of Alzheimer’s disease in people aged 65 years and over. Other forms include vascular dementia, frontotemporal dementia, and dementia with Lewy bodies, as well as dementia as part of other conditions such as Multiple Sclerosis, Huntington’s disease, Parkinson’s disease and HIV/AIDS and Down syndrome. Delay in diagnosis, or misdiagnosis, is common with multiple specialists involved, particularly for rarer forms.

Importantly, persons with YOD are at a very different stage of their life at the onset of their illness when compared with older people. They are typically more physically and socially active, they have younger partners and children, are still working, still driving, have significant financial commitments and do not fit into mainstream dementia services.

The burden associated with dementia at a young age is substantial. Unplanned losses may include income, work, self-esteem and a sense of purpose, with future plans being no longer viable. Changes encountered may mean carers who are partners have the double responsibility of caring for the person with dementia as well as raising children and managing finances. Friendships may become strained as people may struggle to accept that younger people can have dementia and children may have strong reactions to a parent when they become unwell, particularly if they have behavioural symptoms.

Intellectual Disability

Among people with Down syndrome, Alzheimer’s disease is more prevalent and occurs at a much younger age. About 25 percent of adults with Down syndrome who are 40 years and over and about 65 percent of those who are 65 years and over develop Alzheimer’s disease. This is thought to be associated with a gene for amyloid precursor protein found on chromosome 21, with people with Down syndrome having three 21st chromosomes rather than the usual two. Among other adults with intellectual disability who do not have Down syndrome, the prevalence of dementia is comparable with or higher than the general population, though further studies that are of high quality, large scale and collaborative are required.

Regular assessments of people with intellectual disability within disability services provide an opportunity to identify any functional or behavioural decline and provide a prompt for further investigation. Ideally, diagnosis is based on a comprehensive physical, medical, neurological and cognitive assessment with measures of deterioration over time. There are a number of tools available such as the Adaptive Behaviour Dementia Questionnaire (ABDQ).

People with intellectual disability have increased life expectancy due to improved health and social care. As substantial numbers of people with intellectual disability can now expect to outlive their parents and the majority are cared for by family members in the community, families face the anxiety concerning the future care of their child. For those in supported accommodation, extra care needs may trigger the transfer to aged residential care though “ageing in place” models are being developed.

Gay men and Lesbians, Bisexuals, Transgender and Intersex (GLBTI) People

While GLBTI people face similar issues as heterosexuals in living with or caring for someone with dementia, there is increasing awareness of the particular issues and challenges they face as a result of prejudicial social attitudes or discrimination, summarised in Alzheimer’s Australia’s Paper 15. Sexual and gender diversity needs to be recognised and addressed in the provision of health, community and residential care services, including carer support.
The availability of highly active anti-retroviral therapy (HAART) has seen a marked decline in the incidence of brain disorders such as AIDS Dementia Complex (ADC). However, over 50 percent of people living with HIV will still experience some forms of cognitive impairment, commonly referred to as HIV associated neurocognitive disorder (HAND) that may be treated. There are still some people with HIV who will develop AIDS related dementia.

Dementia in Correctional Centres

Of the 10,278 people in custody as of June 2009, there were 203 Aboriginal people over 45 years old and 572 non-Aboriginal people over 55 years old. These are the groups that are most at risk of developing dementia, which was 7.5 percent of the total adult inmate population at that time. The majority of these persons were at the Long Bay Complex. While few in numbers, prisoners with dementia pose significant problems for correctional centres in terms of medical care, personal care and appropriate accommodation. Their care needs require a joint planning approach between NSW Department of Health and Corrective Services.

Non-progressive Cognitive Impairment

Non-progressive cognitive impairment, meeting diagnostic criteria for dementia and resulting in significant functional impairment, may occur after brain insults such as traumatic brain injury, or extensive drug or alcohol use, typically with onset at a relatively early age. With abstinence and dietary support and no further brain insult, these forms of cognitive impairment are often stable or may improve somewhat. Care needs of people with non-progressive cognitive impairment are similar to people with dementia, including the need for community care, case management and supported accommodation and they often face similar challenges to people with younger onset dementia in obtaining a diagnosis and finding appropriate care. This group commonly present during an acute hospital admission and can be estranged from their family, creating an additional barrier to their access to services. Their care needs often test the quality of co-ordination between health (mental health, justice health, drug and alcohol), disability and housing services. A co-ordinated approach is essential as many people currently “fall through the gaps”. Further investigation is needed to determine the clinical characteristics and best-practice service delivery guidelines for this group as well as whether their needs are best met within dementia services. NSW Health is currently exploring the treatment and care pathways for people with alcohol related brain injury.
Policy and planning context

International

There are 35.6 million people world-wide with dementia in 2010 with the number expected to nearly double in 20 years to 65.7 million by 2030 and 115 million by 2050, with proportionate increase much steeper in low and middle income countries. Other developed countries, such as UK, France, South Korea, Norway and Netherlands have recently joined Australia in the development of national plans and the European Commission has initiated the first international plan, the European Action on Dementia.

The UK national dementia strategy, Living well with dementia launched in 2009 was allocated £150M for the first two years to improve awareness, achieve earlier and better diagnosis and improve quality care. A number of reports independently confirmed the urgent need for government action. The National Audit Office stressed the need for improvement in early diagnosis and intervention, that management was disjointed and often ineffective and there were opportunities to improve quality and cost effectiveness. The Committee of Public Accounts concluded that dementia care should be a high priority, the rate of diagnosis significantly improved, a dementia awareness campaign commissioned, people with dementia and their carers given a single professional point to improve coordination, carers needs better addressed, training and outreach services to care homes improved, unnecessary acute care admissions avoided and lengths of stays reduced by better treatment and rehabilitation.

National

In 2005/06 NSW Health led the development of the National Framework for Action on Dementia 2006-2010, endorsed by the Australian Health Ministers’ Conference (AHMC) in April 2006. The Framework provides a structure for the Commonwealth Government and State and Territory jurisdictions to develop a more collaborative response to dementia care and support.

The Commonwealth Government allocated $320.6M over five years in the 2005 budget to Helping Australians with dementia and their carers - making dementia a National Health Priority. Now titled the National Dementia Initiative, it continues to make a significant contribution to dementia services, including Extended Aged Care at Home Dementia Packages (EACH-D), research grants offered through the National Health and Medical Research Council (NHMRC) and funding for three Dementia Collaborative Research Centres (DCRCs), training for aged and community care staff, carers and community workers through the Dementia Training and Study Centres (DTSCs), and support for behavioural management through the Dementia Behaviour Management Advisory Services (DBMAS).

Under NFAD, the Commonwealth Department of Health and Ageing has commissioned KPMG to develop a national dementia pathways project. It aims to map dementia service pathways at a national and state/territory level in order to develop a series of best practice dementia pathways that will assist jurisdictions to identify where the gaps in service delivery lie and in turn assist the Commonwealth Government and State/Territory Governments in service planning. As the development of the NSW Framework and the national dementia pathways projects have similar objectives, KPMG and the NSW Dementia Policy Team have conducted joint state-wide consultations plus case studies in Fairfield, Wagga and Newcastle.
New South Wales

State Dementia Plans
The NSW Government has committed to three state dementia plans that were joint plans between NSW Health and the (former) Department of Ageing, Disability and Home Care (DADHC), now Ageing, Disability and Home Care (ADHC) under the NSW Department of Human Services.

1. NSW Action Plan on Dementia 1996-2001,
2. Future Directions for Dementia Care and Support 2001-2006 ($11.043M over 4 years),
3. NSW Dementia Action Plan 2007-2009,

Under the NSW Dementia Action Plan 2007-2009 the majority of the recurrent Health funds ($1.41 M) was allocated to enhancing and expanding the funding to the Dementia/Delirium Clinical Nurse Consultant (CNC) positions in acute care. In ADHC, recurrent funds are directed to Dementia Advisory Services (DASs) under the Ageing Program. The plan also captured other broader funded initiatives within NSW Health and ADHC (HACC funding) that support the priorities. NSW Health funded initiatives include mental health funds to respond to the needs of people with dementia with persistent and severe BPSD, as outlined in the NSW Service Plan for Specialist Mental Health Services for Older People (SMHSOP) 2005-2015.

The major project under the NSW Dementia Action Plan 2007-2009 was the development of NSW Dementia Services Framework to guide future dementia service planning and investment. It was to provide an evidence based overview of good practice services over the course of dementia and identify current gaps particularly those that exist for diagnosis and assessment and management of complex clients.

NSW Dementia Policy Team
In September 2009, the Department of Health established the NSW Dementia Policy Team to provide state-wide leadership in dementia policy, planning and service development. The major task of the team is to develop the NSW Dementia Services Framework.

Area Health Services planning
Under the first state plan, Area Health Services were encouraged to develop AHS Dementia Action Plans. Under Future Directions, ADHC provided one off funds for the development of joint NSW Health and ADHC planning and service development that led to greater service coordination and attracted additional regional funds. The third plan emphasised the importance of dementia being incorporated into generic planning processes within AHS and DADHC regions. Currently some AHSs and regions have retained joint sector dementia plans, such as the Hunter Dementia Plan developed through the Hunter Dementia Interagency and the four sector plans in South East Sydney Illawarra AHS whereas others have included dementia planning in aged care planning such as North Coast AHS’s new Aged Care Plan.

ADHC HACC regional planning
For the HACC Program’s three year planning cycle that ends in June 2011, regions undertook an analysis of population, service supply and usage data, Local Planning Area consultations and identified service development needs and purchasing priorities for additional services.

Towards 2030: Planning for our changing population
Office for Ageing (OFA), ADHC is responsible for strategic policy and planning in relation to the ageing of the NSW population through the development and monitoring of the NSW Government whole of Government strategy, Towards 2030: Planning for our changing population. Its five strategic outcomes are:

1. Getting in early: planning for change;
2. Improving prevention and early intervention;
3. A productive, skilled and adaptable workforce;
4. Facilitating participation in all areas of society; and
5. Providing quality care and support.

Carers Policy

The importance of carers is recognised at a state level through the NSW Carers Action Plan 2007-2012, the CALD Carer Framework and the recently passed NSW Carers Recognition legislation. Nationally carers are supported and recognised through the National Respite for Carers Program, the Carers Allowance and Carers Payment and through the development of a National Carers Recognition Framework, including the development of national carers legislation. The Commonwealth Government has also responded to the House of Representatives Standing Committee on Family, Community, Housing and Youth report: *Who Cares …? Report on the inquiry into better support for carers*.

Future Planning

As dementia care spans across the health, community care and aged care sectors the development of dementia policy needs to take into account the wider policy context. This wider context is undergoing significant change under the COAG National Health and Hospitals Network Agreement. The current services and programs will need to align with the proposed new structures that include Medicare Locals, Local Hospital Networks and One-Stop Shops of aged care services.

Supporting people with dementia and their families and carers will require co-ordinated planning and integrated service delivery across health services (primary care, aged care and mental health) and community care services that also take account of the important interface with residential aged care.

The projected increase in the number of people with dementia will also require significant workforce investment that targets mainstream and dementia-specific training and resourcing across health, community and residential care services.

There will also be an increased need for a planned response from a range of front-line public and private agencies that are beyond health, community and residential care. These include public housing, police, lawyers, pharmacies and banks. Such an approach is consistent with whole of community responses to substantiative population health issues.
Diagnosis, assessment, information and care for people with dementia, their carers and families is provided through a range of health, community care and aged care services and programs funded by the Commonwealth and NSW Governments that are both mainstream/general and dementia specific (Appendix 3). However, this landscape will change significantly as the Commonwealth Government takes over full funding and policy responsibility for national aged care and primary health services.

In 2008 approximately 60 percent of people with dementia were living in the community and of those, 37 percent were not receiving services; 40 percent of people with dementia were in residential care, making up approximately 55 percent of people in residential care.21

Commonwealth

The Commonwealth is responsible for residential aged care, the largest component of the aged care budget but also plays an important role in community aged care through funding Community Aged Care Packages (CACP), Extended Aged Care in the Home (EACH), Extended Aged Care in the Home –Dementia (EACH-D), and through its joint contribution to the Home and Community Care (HACC) Program. The National Respite for Carers Program also provides a broad range of respite services including dementia-specific services, accessed through Commonwealth Respite and Carelink Centres (CRCC).

Substantially Commonwealth funded NSW aged care initiatives in hospitals include Acute to Age Related Care Services (AARCS) and the Aged Care Services in Emergency Teams (ASETs), funded under the COAG Long Stay Older Patients Initiative.

The 2008 National Partnerships Agreement on Hospital and Workforce Reform has relevance to the care of people with dementia as its four year funding of $165.65M for 2009/10 to 2012/13 enhances four sub-acute areas: rehabilitation, palliative care, geriatric evaluation and management and psycho-geriatric care. The sub-acute care reform implementation will establish or strengthen evidence informed models of sub-acute care, effective service delivery models and sub-acute workforce. Workforce redesign strategies under the National Partnerships Agreement may also be relevant in improving the efficiency and effectiveness of the health workforce.

The Transitional Aged Care Program is a jointly funded service in NSW providing short-term care that seeks to optimise the functioning and independence of older people after a hospital stay. Transition care is goal-oriented, time-limited and therapy-focused. It provides older people with a package of services that includes low intensity therapy such as physiotherapy and occupational therapy, as well as social work, nursing support and/or personal care. It seeks to enable older people to return home after a hospital stay rather than enter residential care prematurely.

The Program facilitates a continuum of care for older people who have completed their hospital episode, including acute and subacute care (rehabilitation, geriatric evaluation and management) and who need more time and support to make a decision on their long term aged care.

Dementia-specific Commonwealth funded services include EACH-Dementia (EACH-D), dementia- specific respite programs under National Respite for Carers Program and DBMAS.

Eligibility for residential care, CACP, EACH and Transitional Aged Care is determined through Aged Care Assessment Teams (ACATs), under the jointly funded Aged Care Assessment Program (ACAP). The core objective of the ACAP is to comprehensively assess the care needs of frail older people and to assist them to gain access to the most appropriate types of care, including approval for...
Commonwealth Government subsidised care services. The assessment process should include the development of a care plan, incorporating a choice of available appropriate services, and managing the care plan to the point of effective referral.

For clients assessed by NSW ACATs in 2007/2008, dementia was the most commonly reported primary diagnosis (20.3 percent). ACATs play an important role in determining the appropriate needs and supports for a person with dementia.

**NSW Health**

NSW Health’s specialist health services for older people, which in part include ACATs, have acute and community components and are multidisciplinary, reflecting the complexity of the health needs of older people. The strength of these aged health services, particularly in metropolitan areas, lies in their integration of assessment and ongoing clinical management through community, hospital and residential care and their capacity to deliver coordinated aged health care across the various funding streams such as health, HACC and CW packaged care. Assessment, diagnosis, treatment and care of people with dementia are core business. There needs to strong links with the national aged care system and the current level of integration maintained.

In recognition of the changing demands resulting from an ageing population and the increase prevalence of complex chronic disease NSW Health has implemented a number of strategies through the Clinical Services Redesign and Severe Chronic Disease Management Programs.

Specific NSW health services for people with dementia include specialist geriatric and psychogeriatric in-patient, outpatient and outreach services, tertiary hospital-based cognitive disorders/memory clinics, Community Dementia Nurses (CDNs), Dementia/ Delirium CNCs in acute care, Specialist Mental Health Services for Older People (SMHSOP), Behavioural Assessment and Intervention Services (BASIS) and Transitional Behavioural Assessment and Intervention Services.

There were 29,385 hospitalisations of persons with dementia in 2006-07, out of which 7.8 percent (2,280 separations) were specifically for dementia or conditions which are often characterised by dementia and where presence of dementia was noted in the hospital record. The remaining 92 percent of hospitalisations were for other conditions, with dementia identified as co-morbid. The type of dementia was not specified in most hospitalisations (75.8 percent ‘not specified’ in 2006-07).

**Ageing, Disability and Home Care**

Ageing, Disability and Home Care (ADHC), Department of Human Services is currently the lead administrator of the HACC Program, in partnership with the Department of Health (DoH) and Transport NSW. Under the HACC Program, people with dementia are considered to be a special needs group that find it more difficult than most to access services. The HACC Program provides key general community services as well as dementia-specific services such as HACC CDNs, DASs, monitoring under social support service type, and dementia-specific respite, centred based day care and case management. NSW Health’s aged health services auspice many of these services. Some DASs are funded through the ADHC Ageing Program (Appendix 4).

From July 2012, the Commonwealth will take over responsibility for HACC aged care services for people 65 years and over (50 years and over for Aboriginal Australians).

In addition to the HACC Program, ADHC also provides support to people with dementia through its direct care provision (Home Care and Community Access) and through services funded by ADHC under Stronger Together and the Ageing Grants Program.

**Alzheimer’s NSW**

In NSW, Alzheimer’s Australia NSW (AANSW) is a significant provider of support to people with dementia, their carers and families through administering the National Dementia Support Program that includes Dementia Helpline 1800 100 500, counselling service, carer education and a Living with Memory Loss (LVML) Program. ADHC also funds AANSW through the HACC Program for activities during Dementia Awareness Week, CALD and Aboriginal initiatives, and recently for YOD research. NSW Health funds AANSW to provide a dementia support group leadership program.
Other agencies

People with dementia, carers and families interact with a range of front-line public and private agencies outside Commonwealth or State funded health, community care, aged care or dementia specific services. These include public housing, police, lawyers, pharmacies and banks. How these agencies respond influences the quality of life of people with dementia, their carers and their families.
The Framework details dementia care in a service pathway from dementia awareness to palliative care. It addresses the needs of people living with dementia and their carers. It also addresses access to quality dementia care for specific population groups comprising people from CALD backgrounds, Aboriginal people, people living in rural and remote communities, people with YOD, and people with an intellectual disability, who identify as GLBTI, or are in correctional centres. It recognises that there are key enablers that span the services pathway.

Development of the Framework has occurred through consultation with clinical and research experts, service providers, carers and consumers. It’s development has been overseen by the NSW Dementia Planning Steering Committee (Appendix 5), ensuring it complies with appropriate planning principles and is consistent with the state and national policy environment on dementia. It was also developed with the support of and advice from the NSW Dementia Expert Advisory Group (see Appendix 6).

Consultation workshops have been conducted for the Framework, involving the participation of near 350 service providers and 50 consumers/carers from across NSW (Appendix 7). They were conducted in inner and outer metropolitan, regional and rural communities, some of which involved focused discussion about the needs of Aboriginal, CALD, YOD and remote community service provision for dementia care.
Community awareness of dementia

Older people are more worried about developing dementia than other conditions such as cancer, stroke or heart disease. Fear, stigma or lack of understanding of dementia can prevent people from seeking help. They may not see any benefit in early diagnosis and fear the loss of independence.

It is crucial that dementia awareness strategies are balanced with messages that reduce fear and stigma associated with dementia and that emphasise that help is available. Lessons can be learnt from the successful mental health campaign for depression, beyondblue.

“It’s a disease not a disgrace” – carer

Increased awareness and reduced stigma will assist people with dementia to continue to participate in activities they enjoy, to remain connected to their communities and to be socially included.

Understanding of dementia varies by CALD group, including lack of awareness and incorrect assumptions. A study of awareness of dementia, stigma and knowledge of services in Vietnamese, Chinese and Italian communities demonstrated differences amongst different ethnic communities groups. People with dementia from CALD backgrounds can be marginalised and isolated in their own communities, are often diagnosed later and often present in crisis.

There is anecdotal evidence that Aboriginal people are aware of dementia and experiencing it within their communities. A person may be affectionately viewed as “Gwarri” - crazy or actually labelled as having “Al”, or the behaviour may be accepted as part of growing old with perhaps less stigma attached to it than for the non-Aboriginal population. However, the perception and meaning of dementia to Aboriginal people, the types of dementia in NSW Aboriginal communities, and where people go for assistance is not well known. These issues are being examined in the Koori Growing Old Well Study (KGOWS).

Dementia risk reduction

There is growing evidence that certain lifestyle factors and health behaviours may help to maintain cognitive health and reduce the risk or delay the onset of dementia, in particular Alzheimer’s disease and vascular dementia. These include combining mental stimulation, social engagement and exercise as well as healthy eating and drinking and prevention or treatment of cardiovascular problems, including blood pressure control in mid life.

The evidence is mostly from population studies and there is no guarantee that changes in lifestyles will improve an individual’s outcome. However, the association is strong enough to relay the important message to the public that what is good for your heart is also good for your brain.

Strategies developed need to address additional barriers people on low incomes face in adopting healthy lifestyles. More broadly, factors throughout the life cycle can impact on healthy brain growth such as maternal health, nutrition, socio-economic inequality, education and employment.

To improve the life experiences of Aboriginal children there is an urgent need to intervene to “close the gap”, in order to maximise brain development and reduce the risk of developing dementia in later life. NSW Government agencies need to continue to work together to improve the indicators reported in Two Ways Together, such as improved maternal health, better nutrition, decrease in childhood infections, supportive parenting to reduce separation, and better early educational opportunities. The Aboriginal

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While cardiovascular risk factor reduction programs may help to reduce or delay the onset of dementia they do not significantly reduce the current demand for assessment, diagnosis and case management.
Maternal and Infant Health Strategy is an example of a successful program that has improved health of Aboriginal women during pregnancy and decreased perinatal morbidity and mortality.58

Concurrently, for Aboriginal people in early and mid-adulthood, the reduction of vascular risk and the prevention of chronic disease is the priority, such as controlling blood pressure, cholesterol and weight gain, stopping smoking and better nutrition. The [Chronic Care for Aboriginal People Program](#) provides direction for NSW. Local solutions resulting from the Walgan Tilly project are being implemented at an AHS level. The [Closing the Gap in Indigenous Health Outcomes](#) Implementation Plan, resulting from the National Partnership has tackling smoking as its first priority, (43 percent of Aboriginal people are smokers).

The rate of significant head injury (i.e., associated with loss of consciousness) was very high (51 percent) in the remote communities of the Kimberley Indigenous Cognitive Assessment (KICA) study compared to non-Aboriginal rates, and may be one of multiple causal factors leading to the higher observed rates of dementia in these communities. KGOWS will examine head injury as a potential risk factor for dementia in urban/rural NSW communities.

Importantly, alcohol related dementia was uncommon in the KICA Study at around 4 percent with low overall rates of alcohol use, dispelling a prevalent myth about high levels of alcohol related dementia in Aboriginal people. Again alcohol as a risk factor is being examined in KGOWS.

For older Aboriginal people, as for all older people, maintaining social, mental and physical activity are important components for successful ageing.
Outcomes

- The public understands memory loss (normal ageing versus early dementia), knows help is available & consults their GP/ Aboriginal Medical Services (AMSs) when concerned.
- Any public awareness campaign is balanced by an understanding that most older people do not develop dementia. However, people are encouraged to plan ahead and put mechanisms in place in case they lose capacity including advance care planning (see information and counselling section).
- The public, including people from specific population groups are aware of the link between healthy lifestyles and reducing one’s risk of developing dementia.
- GPs, AMSs and other health professionals are also aware of the link between healthy lifestyles and dementia risk.
- People who have chronic diseases and are at increased risk of dementia are targeted for education and support for lifestyle changes, including people from CALD and Aboriginal communities. The support available is able to respond to increased barriers faced by people on low incomes and is accessible to rural and remote areas.

Requirements

1. The public are provided with positive messages about dementia, that there are interventions that can make a difference and to see their GP if concerned.
2. Implementation of positive, local awareness strategies in specific population groups.
3. Further research to understand the interaction between risk factors and dementia, and effectiveness of interventions.
4. Incorporation of dementia risk reduction messages into existing public health and health promotion strategies and campaigns.
5. Inclusion of risk reduction into GPs, other primary care professionals, as well as specialist aged health services, and the NSW Transitional Aged Care Program's communication with patients/clients.
6. Identification and support for people most at risk to achieve lifestyle changes, including availability of physical activity programs for older people.
7. Implementation of health and education early intervention programs across the lifespan that reduce disadvantage and optimise cognitive development.
Examples of existing good practice

Community awareness

- Dementia Awareness Week in September each year provides the opportunity for AANSW, DASs, Carer Support Services and a range of other organisations to increase public awareness of dementia through positive media messages such as Life doesn’t stop when dementia starts.
- Australian Indigenous Healthinfonet section on dementia, developed in partnership with AANSW.
- Under the Commonwealth funded round three Dementia Community Support Grants, the New England Division of General Practice will raise awareness of dementia to the Northern Tablelands Aboriginal communities – Taking it to the People project. Intereach Inc will deliver a dementia education project to Balranald and Deniliquin communities. CALD organisations in South West Sydney will increase dementia awareness and early detection with ethnic specific community workers, including a Cambodian welfare worker in the last round and Croatian, Spanish and Assyrian workers in the current round, partnering with the DAS. A recent event attracted 18 Khmer speaking participants.
- The Australian Nursing Home Foundation has produced a Cantonese CD and a handbook for Chinese carers of people with dementia.

Dementia risk reduction awareness

- AA has developed a Mind your Mind campaign program with seven signposts. AANSW also promotes this through the Memory Vans that tour around NSW.
- DASs include risk reduction in their public education strategies, including sessions with using interpreters. Three DASs in Northern Sydney invited Michael Valenzuela to present his findings to 165 attendees, mainly Mandarin speaking members of the Chinese community in Northern Sydney at a Chinese Expo in October 2009.
- South East Sydney Illawarra AHS conducted a Brain Plasticity Seminar in 2009 that attracted over 400 people.
- ADHC produced a Mind Your Memory postcard containing useful tips and contact details developed for people who are worried about their memory, translated into 10 community languages. Office for Ageing, ADHC is currently undertaking two Aboriginal Dementia projects – to develop community information resources including dementia risk reduction and to progress the rollout of the Dementia learning resource for Aboriginal and Torres Strait Islander Communities.

Risk reduction research

- The Dementia Collaborative Research Centre (DCRC), based at the Australian National University (ANU) is undertaking coordinating and promoting reviews and research within the area of early diagnosis and prevention, including risk reduction.

Health and education early intervention programs across lifespan

- Keep them safe: a shared approach to Child Wellbeing 2009. Keep Them Safe resulted in the creation of new systems and services, such as Family Referral Services, Child Wellbeing Units, and Family Case Management. Other existing services have also been funded, expanded or enhanced through Keep Them Safe, including the early intervention program, Brighter Futures, which links vulnerable families with a range of support services including child care, parenting programs and home visiting.
- NSW Aboriginal Community Controlled Health Services have implemented successful programs that target protective factors such as exercise. Aboriginal Health and Medical Research Council of NSW, 10 out of 10 Deadly Health Stories – Nutrition and physical activity introduced targeted antenatal and postnatal programs and a training and support program for midwives and Aboriginal Health Workers. It resulted in improvements in perinatal morbidity and mortality rates and improved access to antenatal and postnatal services particularly where programs link with local Aboriginal Medical Services based in the community.
- NSW Aboriginal Health Awards showcase successful projects that improve health outcomes for Aboriginal people. Shake A Leg Health Promotion - Hunter New England AHS, a school based health promotion program where children are able to take information back to their communities, is one of many examples.
Actions

1.1 Conduct market research to identify barriers/enablers to seeking help with memory loss.

1.2 Develop and implement an evidence based, positive national dementia awareness campaign.

1.3 Promote “planning ahead”- Enduring Power of Attorney (POA), Enduring Guardianship and advance care planning.

1.4 Develop partnerships with service providers for specific population groups to promote awareness of dementia, dementia risk factors and “planning ahead” within these communities, and to develop and/or distribute information resources in consultation with these communities.

1.5 Develop action 1.4 as a key role for Dementia Advisory Services, in partnership with HACC development officers, Aboriginal Access workers and Multicultural Access Project workers. Build DAS network so that consistent, culturally and age appropriate, evidence based messages are promoted.

1.6 Continue research investment into risk reduction through the wider research agenda (NHMRC) and through specific DCRC funding.

1.7 Develop and implement strategies based on research (action 1.6), and on the evaluation of the NSW Health Dementia Risk Reduction Awareness campaign and parallel GP Project to be conducted in the Shoalhaven and Illawarra regions focusing on the link between hypertension and dementia in the 45 years and over age group.

1.8 Educate GPs and other primary care professionals and community care staff regarding dementia, dementia risk reduction, planning ahead and legal requirements for informed consent. Include in medical, nursing and allied health student education.

1.9 Negotiate the inclusion of dementia risk reduction in the existing Aboriginal Chronic Disease Program. Link to local Aboriginal Medical Services, eg. as done with diabetes education.

1.10 Link to healthy lifestyles initiatives. Increase availability of and access to physical activity programs for older people, such as Active Over 50 and Heartmoves.

1.11 Continue to implement early intervention programs that target vulnerable families.

1.12 Continue to implement the National Partnership Agreement on Preventative Health and the National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes.

d Order for listing of actions within each stage of dementia service pathway does not imply priority.
e Includes “linguistically” appropriate.
If people do seek help about memory concerns, they usually consult their GPs who may be hesitant to investigate further and diagnose, due to lack of time, confidence or uncertainty of the benefits for their patients. GPs may have to deal with people who may respond in a distressed manner on receiving a dementia diagnosis so need to be aware of each of their patient’s ability to cope and respond to such a diagnosis. Family members may also be very angry at the possible legal and financial ramifications if a diagnosis is made.

Timely access to GPs can be difficult with long waiting lists or “closed books”. Referral pathways for specialist diagnosis and assessment are neither clear nor available. Medical specialists may also be reluctant to convey the diagnosis to patients and their families. Some GPs and specialists are not aware of the positive impact of support services, their availability, or where to refer to.

“My GP said to me “we don’t like to use the ‘A’ word” – carer.

At the same time, in areas where specialist dementia experts have been available who have made significant efforts to building relationships with local GPs and have provided diagnostic and assessment services, GPs have responded with steady referral rates. In Victoria, over 60 percent of referrals to the Cognitive, Dementia and Memory Service Clinics are GPs.

People with dementia, their families and carers report the benefits of a diagnosis, the relief in knowing what is wrong, the trigger it provides for referral to support services and the opportunity to plan ahead and sort out legal financial and future care arrangements. It also allows for consideration of medication and an opportunity to address issues such as transition from driving or future work responsibilities if a person has YOD and is still working.

Access to specialist dementia health experts varies considerably across NSW with some community clinical aged health services, which in part include ACATs, experiencing considerable demand for diagnosis and assessment and ongoing management. Rural areas have very limited access to medical specialists with existing outreach access unplanned and ad hoc. The lack of specialist positions can result in late diagnosis, poor management of dementia and the absence of clinical leadership to champion the importance of aged and dementia care as a career pathway.

“GPs out here don’t know” – Rural carer.

There is a limited number of Nurse Practitioners (NP) with the speciality of Dementia/Aged Care who can provide an advanced and extended clinical role. They are able to assess, diagnose, treat and manage a person’s care; they can prescribe certain medications, order diagnostic tests and refer to other health professionals. From July 2010 NPs are able to apply for Medicare Provider numbers and Pharmaceutical Benefits Scheme provider numbers.

Interpreters play an important role in dementia assessment, diagnosis and management, particularly when people from non-English backgrounds revert to their original language. There is a reported shortage of interpreters, not all languages are covered and the extra time needed for the interpreter to build trust with individuals is often underestimated.

KGOWS will test the adequacy of the Mini Mental State Examination (MMSE), KICA and the Rowland Universal Dementia Assessment Scale (RUDAS) as culturally appropriate assessment tools for Aboriginal people in NSW. It will collect information of service use amongst older Aboriginal people. It is likely to confirm that Aboriginal people use both mainstream and Aboriginal specific services. However, referral to and use of mainstream services is generally low. For example, Aboriginal clients made up 0.9 percent of referrals to ACATs compared to...
Aboriginal Medical Services (AMSs) also play an important role in the assessment and diagnosis of dementia among Aboriginal people. Among Aboriginal health services in NSW, there are 46 AMSs operating in Aboriginal communities. Consultation with these services could provide greater understanding of the experience of dementia in Aboriginal communities. Staff could also be targeted for dementia training. Access to mainstream general practices that bulk bill is not always available and is problematic in some areas.

People with YOD before the age of 65 can experience great difficulty and delay in obtaining a diagnosis. Some dementias are more difficult to diagnose such as frontotemporal dementia because they can present with prominent behavioural symptoms that are out of proportion to the cognitive signs. Tools such as MMSE are not useful for detecting frontal executive dysfunction. Rather, frontal lobe functioning tests, such as the clock drawing test, and taking a history of symptoms such as disinhibition and language disturbance are important. The lack of affordable neuropsychological services is particularly relevant for people with YOD.

Concern has been raised that screening tools are used as diagnostic tools often with little consistency and training. Screening tools merely alert clinicians that cognitive impairment is present and that further examination is required. This usually requires corroborative history and more detailed testing which may then be followed by repeat testing and investigations.

‘So began a long, long process of appointments and waiting rooms…. When you’ve driven several hundred kilometres to an unfamiliar room in a strange place, then are asked the name of the place you are in and then the name of the street, it seems unreasonable to expect a correct answer. Then when they ask what state I’m in, I want to say a state of frustration.’ – Person with younger onset dementia.

In the consultations for the Framework, carers valued proactive follow up after diagnosis when it occurred while other carers reported they usually made contact only when desperate or in a crisis. Carers consistently report the importance of a key worker, a person with whom they can establish a continuing relationship, who can counsel, problem solve and sort through the myriad of issues that arise. Key workers are also influential in encouraging carers to join in the education and support opportunities. Support of this kind can delay residential care placement.

As dementia progresses a person’s needs are often multifaceted, requiring multidisciplinary assessment and the coordination of a range of health and community care interventions. Case management is a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual’s health needs through communication and available resources to promote quality cost effective outcomes. HACC funded Community Options and Commonwealth funded EACH and EACH-D currently provide case management.

A randomised controlled trial demonstrated that regular assessment and coordinated provision of health and community services substantially improved quality of care for people with dementia and their carers. In another randomised trial, a case manager (a skilled dementia nursing position) working closely with the primary care physician, had regular contact with the person and carer providing education on legal issues, communication and coping skills and individualised advice on managing issues such as repetitive behaviour, personal care, sleep disturbance and agitation, resulting in significant decrease in behavioural symptoms and carer distress.

The key worker role is currently performed by community dementia nurses attached to community aged health services where they exist (Randwick/Botany, Greater Newcastle, Hunter Valley), by dementia counsellor positions (Dubbo, Wagga, Armidale) and to varying degrees by DASs (coverage is limited). DASs may provide initial information and counselling, encourage participation in groups and education and help navigate through the system. These services can also be overwhelmed if there are no services to refer onto, such as Community Options, if complex case management is required. While carers have consistently stressed the importance of proactive follow-up it is difficult for services to provide this due to current demand. As a result, case management is often episodic rather than ongoing.

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Note that the identification of indigenous status may not be reliable – generally Aboriginal people are under-identified in data collections. Staff may not follow recommended guidelines to always ask about Aboriginality and Aboriginal people may be reluctant to identify as Aboriginal in some circumstances.
Outcomes

- Regardless of age, when a person, their family, or carer raises concerns with GP, AMS or other professionals their concerns are taken seriously and investigated.
- A person experiencing cognitive impairment has timely access to a GP who can investigate, assess, and diagnose. For many GPs, practice nurses may conduct some of the initial assessments or
- The GP refers the person to an accessible dementia health expert who can conduct a culturally sensitive comprehensive assessment and diagnose in a timely manner whether the person has dementia and if so what type. The dementia health expert liaises with GPs regarding appropriate investigations, undertakes a culturally sensitive comprehensive assessment and determines the type of dementia.
- A person’s carer is interviewed as part of the assessment and the carer’s own physical and emotional wellbeing is assessed. Strategies are identified to maintain their health and wellbeing.
- Once the diagnosis is made, the person, carer and/or key family members are informed sensitively through a case conference. However, if the person communicates preference not to know of a diagnosis, this is respected.
- There is efficient and clear communication between the GP and the dementia health expert.
- Persons with dementia, carers and/or key family members are included in the development of the multidisciplinary care plan, are given a key person for further contact when issues arise & are advised when to expect a review of their care plan. They are provided with timely and culturally sensitive information.
- People with dementia, carers and/or family members are proactively followed up after diagnosis by a key worker with whom they can build a continuing relationship. The key worker is a person with nursing or allied health qualification, skilled in dementia care and who works closely with the person’s GP.
- As care needs increase and/or become complex, the key worker is a case manager who negotiates an individualised appropriate package of care that is monitored, reviewed and includes access to health care.

Requirements

1. Referral protocols are agreed to at a network level and promoted.
2. GPs, AMSs and/or their practice nurses respond to concerns, carry out investigations, diagnose or if preferred, refer to a dementia expert for diagnosis and are involved in the ongoing care plan in an integrated care model. Some GPs will choose to take the lead in diagnosis and case management, with effective use of MBS items such as health assessments, management plans and team care arrangements. They may delegate the bulk of assessment and management to specifically trained practice nurses. GPs could be given enhanced status subsequent to training and provided with greater incentives to take the lead through adequate remuneration for assessment and carer consultation time.
   Others GPs can be supported through integrated care models with specialist aged health services resourced to include dementia health experts such as CDNs and allied health positions for a comprehensive assessment and consultation with specialists such as geriatricians if diagnosis is unusual or difficult, or psychogeriatricians for psychotic or severe behavioural issues.
3. Dementia experts trained in diagnosis and culturally sensitive comprehensive assessment are accessible in a timely manner. They work with Aboriginal health and CALD liaison officers.
4. A key worker with a health qualification, who is skilled in dementia care and who works closely with the person’s GP/AMS, proactively follows up after diagnosis and builds a continuing relationship. The key worker case manages care needs as they increase and/or become complex.
5. Generic health and community care workers, including Transitional Aged Care workers are trained to recognise symptoms of possible cognitive impairment, consult experts and refer (with consent).
6. Professionals are trained in the appropriate use of screening tools to improve competency and interpretation.
7. GPs, health and community care staff are trained in advance care planning and know the legal requirements.
Examples of existing good practice

Integrated care models with GPs and clinical aged health services for diagnosis and assessment

- The Hunter sector of the Hunter New England AHS operates a shared care diagnosis, assessment and management model between GPs and a community dementia service attached to ACAT positions operating from multiple sites, located at Newcastle East, Newcastle West, Westlakes, Eastlakes, Nelson Bay, Raymond Terrace, Lower Hunter and Upper Hunter. GPs are encouraged to request relevant blood tests, a CT brain scan and to refer to the CDN to carry out a functional and psychosocial assessment, preferably in the home. If requested by the GP, the person and family/carers are then seen in a community based clinic by the Geriatrician and CDN where a complete diagnosis is made and management plan developed. The person and family are informed of the outcome of the assessment, which may include the diagnosis if requested, following a careful history from the patient and his or her family/carers. Issues such as support services, driving and future planning are discussed. A report is sent back to the GP, including a problem list and management plan, and the person and family/carers are followed up by the CDN two to three weeks after diagnosis where there is an opportunity to discuss the diagnosis and plan for support and education. The nurse is then available for case management, depending on the severity of behaviours, psychological issues or carer stress. Referral to a BPSD specialist (psychogeriatrician, DBMAS, BASIS) is made for difficult behavioural and psychological problems or dual diagnosis. Referral to neuropsychology is only made by medical specialists and is required in only 5-10 percent of cases. As services have been in operation for 3-4 years, they are known to GPs, who are not reluctant to make referrals, currently averaging about 20 a month (mostly, but not all, for cognitive impairment) in the Westlakes area with a total population of 80,000. The CDNs and practice nurses have integrated their practice in geographical regions to support primary care in their ongoing case management role, with practice nurses contacting the CDN regularly for advice.

- The New England Division of General Practice runs a Memory Assessment Program Support Service (MAPSS) that employs coordinators whom GPs refer to and who makes contact with families prior to the family meeting with the geriatrician. GPs are invited to a case conference, which they usually attend and are remunerated through MBS GP Management Plan and case conference items. The Division also hosts the AANSW Dementia Educator and Carer Support Officer who is introduced and follows up with families.

- North Coast AHS Dementia Outreach Service provides memory clinics in partnership with the Northern Rivers General Practice Network. They provide a comprehensive biopsychosocial assessment following a GP referral with information on medical history, current medication, and outcomes of investigations. The person with spouse/family member/carer is seen by a registered nurse, clinical gero-psychologist and social worker during a 2-3 hour clinic visit. The findings and recommendations are shared with person and family and a report is sent to the GP within two weeks. The team follows up the person and family to provide information and links to further education and support services.

- Hornsby Ku-ring-gai Hospital (HKH) Memory clinic in North Sydney Central Coast AHS. Pre-screening is completed by the GP, while the CNC develops a comprehensive clinical profile including cognitive testing. The staff specialist confirms the diagnosis and develops recommendations.

- North Sydney Central Coast AHS operates an early intervention memory screening service that is nurse led and involves cognitive screening and functional assessment to assist GPs with the early diagnosis of dementia. GPs receive a comprehensive report and the client receives reassurance, guidance and support.

- North Coast AHS provides a NP Aged Care outreach service in the ED at Port Macquarie Base Hospital and a NP Psychogeriatric/ Dementia service in the hospital setting of Tweed and Richmond Networks. Both services provide assessment, diagnosis, and management of dementia/ delirium and age related complex presentations in the hospital environment and the ED.

Comprehensive model for a specific group

- The AIDS Dementia & HIV Psychiatry Service model comprises a comprehensive state-wide network of services established to provide specialist consultation, assessment, diagnosis and management for people with complex needs usually associated with a diagnosis of AIDS Dementia Complex (ADC), or cognitive impairment and/or a HIV related psychiatric condition.
Screening and assessment tools

- Under the first NSW dementia action plan, clinicians in Sydney South West developed and validated the Rowland Universal Dementia Assessment Scale – RUDAS for use in multicultural populations so that there was not the bias of language and education found in other assessment tools such as the MMSE. It has been further validated in Melbourne and Adelaide, confirming its accuracy for a range of cognitive functions similar to the MMSE and General Practitioner Assessment of Cognition (GPCOG).

- Screening and Diagnostic Assessment of Non-English Speaking People with Dementia provides guidelines and system recommendations for practitioners, service managers and policy makers.

- The GPCOG has been designed and validated as a screening tool for cognitive impairment in primary care. It is available free of charge in many languages.

- The Dementia Outcome Measurement Suite (DOMS) project commissioned under the Australian Government’s National Dementia Initiative, has developed a standard suite of instruments to encourage clinicians to ‘talk the same language’ by using the same instruments as much as possible. The website includes critical success factors for assessment.

Interpreters

- NSW Health is funding the training of health care interpreters in dementia assessment.
Actions

2.1 Promote diagnosis and assessment referral protocols to key health services (GPs/practice nurses, AMSSs, Medicare Locals, Hospital Networks, pharmacies, etc.) and to community service contact points such as CRCC and proposed One Stop Shops.

2.2 Provide GP/practice nurses and AMSSs with training opportunities and incentives to undertake dementia assessment, diagnosis and ongoing management. Include guidelines, screening instruments and referral forms in software used by GPs. Adequately remunerate GPs for time spent in assessment, carer consultation, diagnosis, information, referral and joint care planning.

2.3 Develop integrated models between GPs, AMSSs and specialist memory assessment and review teams (SMART), involving specialist CDN (CNSs, CNCs, NPs) and allied health positions and access to appropriate specialist doctors.

2.4 Quantify resources for equitable access to specialist services in the dementia population planning model that includes viable models for rural and remote areas, such as NP models, and that addresses the needs of specific populations.

2.5 Increase access to specialist assessment and diagnosis services (eg SMART) through increasing CDN (CNSs, CNCs, NPs) and/or allied health positions, reviewing current workforce and developing incentives to recruit and retain community Specialists - Geriatricians, Psychogeriatricians (including better access through better use of telemedicine).

2.6 Develop positions for Aboriginal liaison officers within ACATs in areas of established need.

2.7 Increase coverage of key workers. Include key worker in dementia population planning model.

2.8 Pilot an early intervention brokerage model to increase access to key workers for CALD population groups.

2.9 Provide and promote dementia training opportunities for generic health and community care workers.

2.10 Include in the role of the community dementia CNC the provision of clinical advice, consultation, professional support and education to others, such as generic health workers in community teams and practice nurses (see requirement 5).

2.11 Expand acute delirium/dementia CNC/NP positions to provide clinical advice and consultation, professional support and education to staff within hospitals.

2.12 Develop evidence based guidelines for targeted assessment to detect dementia and train health professionals in the appropriate use of assessment tools. Promote use of the Dementia Outcomes Measurement Suite (DOMS) and delivery of e-learning.
Assessment processes through ACATs and HACC services and/or a dementia diagnosis should trigger access to information, counselling, carer education and ongoing support. Information, counselling and education can empower carers, positively influence future outcomes and improve the quality of life for people with dementia and carers. While still retaining capacity, a person with early dementia as well as family members should have the opportunity to discuss future care and make important legal and financial arrangements.

“It’s not what people can’t do but more what they can still do that we have to concentrate on” – DAS Worker

Information, counselling, support and education for carers make a difference. A randomised controlled trial found sessions of individual and family counselling, support group participation and continuous ad hoc telephone counselling resulted in a 28.3 percent reduction in the rate of nursing home placement or one and a half years delay in admission, with the most important aspect being changing the carers reaction to memory and behaviour problems.64 A randomised trial of intensive ten day residential carer training conducted in Sydney demonstrated a significant reduction in carer stress, delay in nursing home admission and significant cost savings.65

In a UK study51 the greatest sources of support identified by people with dementia following diagnosis was access to other people with dementia and their families who provided emotional peer support, information, advice and practical tips. In NSW and Australia, this type of support is provided through the LWML Programs.

Information to CALD communities needs to be presented through a variety of channels. Cultural-specific services such as Greek Welfare, Co.As.It and Migrant Resources Centres, as well as ADHC community access workers, are often central points for services and information.5 At a family level, it is important for professionals to identify the family decision maker so that appropriate information is conveyed to the relevant person who may be different from the primary carer.6

Aboriginal workers report the need to develop dementia information that is specifically targeted to Aboriginal people, using plain language, pictures and Aboriginal images. These need to be distributed to Aboriginal organisations and to Aboriginal liaison officers who are key contacts in Aboriginal communities.

People with YOD have specific information and counselling needs. Relationship breakdown and financial adversity are common. People may also experience demotion, early retirement, inability to access superannuation or selling of the family business as an outcome of cognitive impairment. Access to genetic counselling and testing will be relevant for some people. Currently genetic testing and counselling practices are inconsistent across states.
Outcomes

- People with dementia, carers and/or family members are given appropriate culturally-appropriate verbal and written information on diagnosis. They are given adequate time and ongoing opportunity to discuss the information that includes:
  - Signs and symptoms of dementia, the anticipated course and prognosis, treatments, management of co-morbidities.
  - Specific information on wills, Enduring POA, Enduring Guardianship and advance care planning.
  - Driving.
  - An emphasis on maintaining quality of life, social engagement, independence and function.
  - Local community support services.
  - Financial assistance.
  - Work implications for people with YOD.
  - Needs of children for people with YOD.

- People with dementia, carers and/or family members may experience grief, loss, conflict and/or relationship breakdown. They are informed of and if they choose, referred to telephone, face-to-face, individual or group-based counselling and this is available for both people with dementia and their carers.

- Carers are encouraged to think about their own physical and emotional well being, to involve other family members, to maintain friendships, to make use of respite and other support services and take up available educational opportunities.

- People with dementia, carers and/or family members have the opportunity to meet other people with dementia and their families following diagnosis.

- Carers are provided with support to enable them to maintain their own health, social and emotional well being.

- People with dementia, carers and/or family members are told whom to contact when issues arise and are proactively followed up after diagnosis. The key worker is a person with a nursing or allied health qualification, skilled in dementia care and who works closely with the person’s GP.

- If competent, people with dementia appoint an Enduring POA, Enduring Guardian, complete an advance care directive and/or discuss their future preferences for health care treatment with their family/GP. People understand their legal right to accept or refuse treatment.

Requirements

1. Dementia experts to provide information following diagnosis at clinic and/or home visit.
2. Proactive follow up from identified key worker.
3. Culturally and age appropriate written and verbal information provided.
4. Culturally and age appropriate education and counselling for people with dementia and their carers (ind./group, telephone).
5. Range of appropriately targeted carer support groups responsive to the diversity of local need – eg Aboriginal, CALD, YOD, male.
6. Carer education sessions.
Examples of existing good practice

Education
- The Living with Memory Loss (LWML) Program is a one-morning-a-week, 7-week course to educate people with dementia and their principal carers to maximise their health and well-being. A Chinese specific program is being conducted in Burwood. LWML Program is part of the Commonwealth funded National Dementia Support Program (NDSP) that includes:
  - the National Dementia Helpline 1800 100 500.
  - Information, Awareness, Carer Education and Training.
  - Dementia & Memory Community Centres NSW.
  - AANSW dementia library.
- Components of the program have been evaluated.1,2,3
- YOD resources on AA website.

Counselling
- AANSW counselling service.
- National Carer Counselling Program.
- MBS funded counselling for psychologists.
- Koori carer yarning camps run by Carers NSW to give carer the opportunity to talk to others and participate in creative group activities.

Carer support
- A range of Carer Support Groups run by a variety of organisations and supported by AANSW that include YOD specific support groups and a group for children of people with dementia.
- Carer Life Course Framework - web based e-learning tool to map the life course of the caring role so that relevant services and supports can be accessed at appropriate stages.
- Aboriginal Carers Support Guide and Aboriginal Carers Support Groups, such as Penrith.
- Carer breaks and retreats that provide the opportunity to meet other carers and for education and respite.

Advance care planning
- The NSW Health advance care planning website provides information and tools to the public with links to local AHS information sites, associated websites and tools for health professionals.
- Sydney South West My Wishes website provides ACP information for public, GPs, health, community and residential care staff.
- The Planning What I Want website developed by the Central Coast DAS provides information about Advance Care Directives.
- Advance Care Directives forms for community and residential care use on ASLaRC website.
- My Health, My Future, My Choice is a book that explains what people can do to make sure their health and care choices will be known in the future and includes an advance care directive form.
- ADHC resources include Planning Ahead Fact Sheets available in English, Arabic, Croatian and Italian, a research report on Planning Ahead in Culturally and Linguistically Diverse (CALD) Communities and Taking Care of Business: Planning Ahead in Aboriginal and Torres Strait Islander Communities (A4 booklet - for service providers), and Taking Care of Business: Planning Ahead in Aboriginal and Torres Strait Islander Communities (A5 booklet - for community members).
- Capacity Toolkit – NSW Attorney Generals Department.
- Legal resources on AANSW website.
### Actions

3.1 Train and resource GPs/practice nurses to provide or refer for information and support.

3.2 Increase access to a key worker.

3.3 Provide comprehensive coverage of Dementia Advisory Services with strong links to AANSW.

3.4 Continue to develop and promote accessible culturally and age appropriate information resources.

3.5 Continue to promote Dementia Helpline 1800 100 500 and counselling services through AANSW.

3.6 Promote the National Carers Counselling Program including access to bilingual counsellors and Koori carer yarning.

3.7 Review availability of a range of culturally and age appropriate carer support groups and encourage expansion if required.

3.8 Expand access to LWML Programs for people in early stages to include people from specific population groups.

3.9 Provide access to and promote a range of carer education sessions.
The majority of people with dementia are supported by family and friends, usually termed carers. Family carers are the cornerstone of community care. About 37 percent of people with dementia received no formal care in 2008 and the use of formal support services is often low, particularly by people from CALD backgrounds.

An important source of support for carers, linked to higher life satisfaction, is support provided by other family members, friends and neighbours. Carers have reported wanting more informal support.

Where people live, the physical design of their homes and the outdoor environment, their proximity to shops and health care can influence how well they can navigate their communities and remain integrated and independent. The design of services such as centre-based day care can also maximise their therapeutic capabilities.

People with dementia need support to transition from driver to non-driver and to have access to affordable transport alternatives.

As more people with dementia live alone, demand will increase for suitable community models and access to services that provide nutritional support.

“... support has kept me sane.”
– Dementia carer.

Access to mainstream services is dependent on knowledge, partnerships and cultural competence. Information about services needs to reach CALD and Aboriginal people. CALD and Aboriginal people may be likely to approach an identified CALD or Aboriginal service in the first instance for support in accessing a mainstream service. Therefore it is crucial that mainstream services reach out with culturally appropriate information and develop partnerships with CALD and Aboriginal services. Models need to be explored that increase access to key workers for all specific population groups.

Cultural competence training for mainstream services will increase the likelihood that the service is sensitive to the needs of CALD and Aboriginal people. It is important that service providers understand the cultural practices and communication protocols of the local community. For example, avoiding eye contact may be seen as respectful and an older person may be reluctant to talk to a younger person about “older people’s business”.

People with YOD and their carers also struggle to access services as they do not identify with services labelled with words such as frail, aged care, or disability.

Timing appears to be important. Carers who utilise home support services earlier in their carer careers are more likely to delay institutionalisation. However, more research is needed to identify at what stage should support services be introduced to deliver the most benefit. A recent study of the uptake of residential respite care by people with dementia confirmed previous findings that has found that people with dementia who use short term residential care are more likely to enter permanent residential care. These services may act as “stepping stones” to permanent care.
Developments in the use of assistive technology need to be monitored as potential mechanisms for supporting people at home and reducing carer stress, as reported in a recent Scottish review of the benefits of Telecare. People with dementia are at increased risk of emotional, financial, physical and sexual abuse or neglect. The NSW Government released an Interagency Protocol for responding to the abuse of older people to assist workers in a range of agencies in responding to these risks. Its principles are also applicable to younger, vulnerable adults. Other States have developed advice and educational services such as the Queensland Elder Abuse Prevention Unit (EAPU). Catholic Community Service’s Severe Domestic Squalor Project also highlights the challenges of supporting people with cognitive impairment who are living in domestic squalor where health, ability to receive services or the ability to live in the community is jeopardised.

People with dementia, as they experience progressive decline and loss of skills of daily living, are more likely than people without dementia to enter residential care. Systematic reviews undertaken on transitions in care of people with dementia have found consistent predictors of entry to residential care (noting the lack of research into the predictors of community care use):

- Dementia severity, cognitive decline and functional impairment;
- BPSD and level of distress with BPSD; and
- Carer’s health and burden.

These findings point to the importance of carer education and support for preventing and dealing with BPSD.

Respite care is complex. While it is highly valued, with reported unmet need, available services are under-utilised, particularly from people from non-English speaking backgrounds. More flexible respite services may better meet the needs of people with dementia and their carers. Meaningful, culturally and age appropriate activities for people with dementia are important to carers.

A recent needs analysis in Metro South region of ADHC found that flexible services when and where the clients and their carers are able to access them was the most commonly expressed need across all consultations. This was true for both generic and dementia-specific services generally.

One of the consistent messages from the NSW consultation about the Framework was that the limitations on staffing and expertise in current community services models meant people with dementia and their carers were less likely to be able to access community services such as centre-based day care as their needs increased. Mainstream services could not manage the extra support required and dementia-specific services could not cope with people with BPSD or high physical needs. Appropriate residential respite for people with BPSD can be very difficult to obtain.

People from CALD backgrounds are often reluctant to move to a dementia-specific service which they view as stigmatising. An alternative model is for an appropriately trained worker to help maintain the person in their existing service.

Another issue consistently raised in consultations was the difficulty in giving up familiar services to move to packaged care and the variation in the rules surrounding the transition.

While service providers welcomed the growth in packaged care, the shortage of supply was noted and concern expressed over the plethora of new providers. Each frequently provides relatively few packages with separate infrastructure costs and often with no connection to existing services. The lack of centralised systems for allocating vacancies has led to a perceived lack of prioritisation based on need, and disadvantage for people who do not have assertive or well-educated carers able to navigate the complex care system.

The availability of community service models for people with YOD and that cater for more active clients is varied. People with YOD and their carers are reluctant to use services that are geared towards much older people. AANSW has been funded to conduct a two-year research project on improving services and support to people with YOD.

The provision of dementia services in rural and remote areas has its own set of challenges and improving access to aged care services, let alone dementia-specific programs, is a priority.

A comprehensive analysis of needs of people with dementia and their carers in the Metro South Region of ADHC is now available. Extra barriers to accessing formal support exist for specific groups:
people from CALD backgrounds (an exception is ethnic-specific CACP services and other brokerage models that can match staff to clients, which have been well utilised where available);
- Aboriginal people, who may not know of services or who may mistrust mainstream services; and
- those who cannot access transport which is critical for accessing services.5

In some areas dementia services are well networked and coordinated across health, community care and residential care. These networks, usually coordinated by DASs and/or dementia/delirium CNCs, report benefits of greater communication and cooperation, easier referral processes, joint dementia planning and collaborative development of new service models.

Some areas hold regular case conferences involving multiple service providers.

### Outcomes

- Communities support people with dementia and their carers to remain socially active and engaged in community life.
- People with dementia and their carers can determine how culturally and age appropriate high quality services are delivered so that services can respond flexibly to their diverse and changing needs.
- People with dementia and/or their carers have access to culturally appropriate advice on promoting dignity, independence and safety.
- People with dementia living alone without family support have access to services that can monitor their safety, support them to remain in the community and assist in the transition to more supported accommodation when required.
- People with dementia receive timely and culturally appropriate responses from agencies to protect them if they are at risk or have been subject to abuse.
- People with YOD are supported in the workplace to review and modify their responsibilities.
- Carers are valued and treated as partners in care.
Requirements

1. Identified key worker available for family to contact and assist with linking to services.
2. Accessible up-to-date information on local dementia services available and promoted.
3. A well planned, networked and coordinated service system.
4. Services that can provide a timely and flexible response to diverse and increasing needs.
5. Capacity to support people with dementia to remain for longer with their familiar support service.
6. A range of accessible, culturally and age appropriate, mainstream community care services competent in person-centred dementia care available for people with non-complex care needs.
7. A range of accessible, culturally and age appropriate, person-centred dementia-specific services available for people requiring specialised dementia care.
8. Accessible, flexible, culturally and age appropriate person-centred case managed packages of care for people with dementia with complex care needs.
9. Access to evidence based advice on promoting dignity, independence and implementing safety in the home and other community settings.
10. Accessible advice on responding to the abuse of vulnerable adults.
Examples of existing good practice

Information
- The Eastern Sydney DAS provides web based dementia services information linked to Google maps.
- The Eastern Division of General Practice provides links to services on its website.
- Aboriginal specific DAS – Walgett and Dubbo.

Respite and social engagement
There are an increasing range of respite options including in-home, residential, overnight/weekend stays in day centres or cottages, mobile services, emergency respite, respite for working carers, as well as social outings, holiday programs and weekend retreats that may include carers/family. There is also an increasing number of innovative, flexible models aimed at meeting diverse needs including people with YOD or with BPSD, such as twilight tours, men’s sheds, leisure “buddy” service and social outings.

A sample of existing services is below:
- The Ella Centre in Metro South has developed a model of care for people with YOD that emphasises physical activity through community participation, employs a person-centred approach, responds to needs of working carers through operating between 8am - 5pm allowing carers to drop off at a time that suits them, and has a higher ratio of staff to accommodate people with BPSD. The Ella Centre has also established D-Caff, a monthly informal gathering on a Saturday morning for carers and people with dementia.
- Saturday Horizons Program at the Tom O’Neill Centre in North Sydney offers excursions and in-centre activities decided by a small group of clients.
- On Track Dementia Café at Kokoda Café in Rhodes Park at Concord provides opportunity for people with dementia and carers to meet informally.
- Art gallery visits, inspired by the Artists for Alzheimer’s™ program developed by John Zeisel, president of Hearthstone Alzheimer Care.
- The Mobile Respite Team, a short term service in the Bega Valley Shire, provides specialist information, support and education about living with and caring for a person with dementia and provides direct care for a person living with dementia who exhibits BPSD. The two team members provide education and support for both the carer and the person with dementia in their own home.

Service models
- Defining Dementia Service Appropriate Models: Challenging Behaviour and Younger People with Dementia.
- CALD Dementia Strategic Model based on research with Italian, Chinese and Vietnamese communities.
- Aboriginal Home Care, such as Mari Ma branch in Maitland, Wangary in Penrith, Ngangana in Dubbo and Weja in Dapto. Aboriginal access officers can also assess people for Aboriginal specific Community Options. Aboriginal Home Care also delivers Aboriginal CACPS, EACH and EACH-D.
- Aboriginal specific community organisations also deliver packaged care – such as Awabakal Elders Community Aged Care in Wickham, Biripi Aboriginal Community Care in Purfleet, and Allira Aboriginal Community Care in Dubbo.

Dementia service networks
There are dementia service networks located throughout NSW that provide an important linkage for dementia services to keep up to date on developments in local service activity and discuss issues in service coordination. An example is the:
- Central Coast Primary Dementia Care Network – a network of key organisations and individuals responsible for the care of people with dementia on the Central Coast.
- National Cross Cultural Dementia Network provides advice on equitable access to people from CALD background.

Case conferences
Weekly case conferences are held in the Hunter involving a geriatrician, CDNs, ACAT, COPS, CACP and EACH case managers and the Dementia Monitoring Service.
**Actions**

4.1 Clarify the role of DASs and CDNs as key workers.

4.2 Increase coverage of key workers. Include in the dementia population planning model.

4.3 Include the responsibility for updating dementia service information in the role of DAS that is then promoted through multiple links including existing CRCCs 1800 052 222, Dementia Helpline 1800 100 500 and proposed One Stop Shops, and Medicare Locals.

4.4 Develop a dementia population planning model to guide future funding of community support services.

4.5 Include quality dementia care in any community care standards developed.

4.6 Include the development of network-level planning and service networks in the role of DASs.

4.7 Promote the development and implementation of innovative models of care that respond to diverse needs of specific population groups.

4.8 Develop and implement affordable and accessible transport options for people with dementia no longer able to drive to promote social inclusion and access to services.

4.9 Evaluate the use of 500 consumer directed care (CDC) flexible care places and 200 consumer-directed respite care places for people with dementia.

4.10 Address the needs and access to services of people with YOD in particular, following the reorganisation of services under the COAG reforms, noting the outcomes of AANSW’s YOD research project.

4.11 Expand access to culturally and age appropriate support services, the range of respite options and flexible packaged care.

4.12 Expand the availability of community support models suitable for people with dementia living alone.

4.13 Review existing funding and eligibility requirements to enable greater flexibility in service delivery.

4.14 Increase access to evidence based advice on promoting dignity, independence and safety through including allied health dementia experts in the dementia population planning model.

4.15 Provide access to evidence based assistive technology and support further development of the evidence base.

4.16 Increase access to advice on responding to the abuse of vulnerable adults.
Peter’s story

Peter is a fit, strong, social 72-year-old man who has always been very active. He has frontotemporal dementia. He and his family noticed changes in his 50s and he was finally correctly diagnosed when he was 66. His cognitive impairment is now quite severe. He has lost his motor planning ability, ability to speak coherently, has difficulty understanding, cannot recognise objects and is doubly incontinent. He can be agitated in the evenings and aggressive with staff trying to provide personal care. However, he loves company and finds classical music soothing.

Peter recently entered a residential care facility. One day he collapsed and was taken to the Emergency Department where he experienced his first hospital admission with acute renal failure. His second admission, following repeated ED presentations when he pulled out his in-dwelling catheter, was when his family insisted that an ambulance was called as he was in extreme pain and unable to move. In ED after a long wait when he was sweaty, quiet and was in atrial fibrillation his wife mentioned that his catheter bag was empty. He was found to be in severe urinary retention. His catheter was removed and during his stay he was prioritised for a Transurethral resection of the prostate (TURP) for an enlarged prostate.

During his two admissions Peter was cared for in three different wards – a behavioural unit in a respiratory ward, two sessions in the acute aged care ward and post-surgery in a urological ward. Throughout he was ‘specialled’ frequently by nurses, but sometimes by security guards who would watch him but with no involvement in his care.

His wife, who works fulltime, took carers and long service leave to be with him and, with their two children who also work, tried to roster themselves to cover as much as of the day and evenings as possible.

On one occasion after he had climbed over the bedrails he was sedated with enough haloperidol to be “knocked out unconscious” for four days. In ED he was given three consecutive doses where he was knocked out again for 24 hours. When visiting him after surgery his wife found him tied by the hands and feet to the bed. No consent was obtained. “It was the most distressing sight I have ever witnessed – his fear was palpable”. Over the following weekend he was allowed to have his wrists untied if a family member was present.

During his recovery in acute aged care, his wife said “the team was magnificent once they gradually got to know Peter, and once they got to know us, we were able to work out the best way to look after him together. He had his own room with a big window overlooking a garden and he could see the sky. An ensuite meant that I and the kids could spend time showering him and he could listen to his music without disturbing others”.

“I was concerned at the money spent on ‘specialling’. What was needed was an extra pair of hands not just an extra pair of eyes – someone with the skills to engage with Peter and provide care. Peter is physically active and strong but significantly impaired. It must be recognised that managing people like Peter requires a specific specialised skill set, adequate staffing, an attitude of wanting to understand him as a person, his particular needs and preferences and a willingness to work collaboratively with the family”.

Improving the hospital experience for people with dementia is a critical priority area for the Framework. Older people with dementia will experience other chronic and acute illnesses that are common to all older people.

It is crucial that cognitive, physical or behavioural changes are not just dismissed as dementia but are investigated and appropriately treated.
Dementia increases the risk of delirium with any accompanying illness. A person’s medical condition and/or the increased confusion and behavioural disturbance related to delirium can precipitate an admission to hospital. The person’s confusion and behavioural disturbance can then be exacerbated by an unfamiliar and frightening environment.86 The reduction, recognition and management of delirium either at or during admission is a major policy, training and design issue for hospitals in NSW, confirmed by concerns raised in the consultation workshops.

People with dementia are at increased risk of falling. Injury as a result of falls is a common reason for admission and may occur while in hospital. Increased risk of falling and accompanying delirium means that a person with dementia may require very careful supervision, resulting in the use of restraints or “specialling”. Delirium and dementia are frequently poorly identified and coded.

Increased care needs combined with communication issues of people with dementia can challenge acute care staff, particularly when combined with ageist attitudes and negative stereotypes.

“I don’t think she would have been fed if I wasn’t there.”
– Dementia carer

Few acute wards are designed appropriately for people with cognitive impairment, despite known high rates of dementia and delirium in acute hospital wards. Rural and remote areas and some metropolitan hospitals lack geriatric-specific wards and geriatric expertise, leading to a poor knowledge base of geriatric nursing and care needs compounded by an unsatisfactory environment.

Hospitals can be daunting places for Aboriginal people away from country or family, with few Aboriginal workers or fellow patients who share the same kinship. Older Aboriginal people may fear hospitals as places to die or where children were historically removed. Staff lack cultural awareness training and may be critical of the number of family visitors.

There is ongoing discussion on the definitions of acute versus sub-acute and what should be managed in these care types under the sub-acute section of the National Partnership Agreement on Hospital and Health Workforce Reform. Practice and ownership between aged health and mental health services vary in managing BPSD in hospitals.

Positive changes in hospital care have been made in response to the increasing demand of an ageing population plus the recognition that older people can quickly decline functionally as a result of being in hospital.87 Initiatives have been introduced to avoid unnecessary transfer to hospital, to avoid prolonged ED stays, to provide more timely access to appropriate treatment, to increase rehabilitation opportunities, to reduce lengths of stay and to provide better links to community care on transfer. These initiatives include the ASETs, Medical Assessment Units (MAUs) and AARCS.

Initiatives in improving dementia care need to be part of an integrated comprehensive approach to improve quality care for older people. The projected dementia increase will be driven by the very old age groups where cognitive impairment will be one of several risk factors such as functional impairment and impaired mobility that are part of common geriatric syndromes (pressure ulcers, incontinence, falls, functional decline, and delirium),88 that are managed by specialist aged health services. A significant number of people in the current target groups of the Severe Chronic Disease Management Program (SCDMP) will have dementia that will complicate the diagnosis and management of their physical illnesses. Any pre-existing chronic illnesses, especially mental illnesses may place extra demand on services.

People with dementia have longer lengths of stay than people without dementia.10 The Dementia Services Hospital Project has found that people with YOD and psychiatric and behavioural problems can have very long stays.89 Feedback from consultations noted the need for timely Guardianship applications and Guardianship Tribunal responses to improve timely transfer of care.

NSW Health’s pending policy direction on care coordination that addresses planning from admission to transfer of care is particularly relevant to people with dementia with complex health and community care needs.

People with dementia are particularly suited to initiatives such as Hospital in the Home (HITH) that provides treatment outside of hospitals so that they remain in familiar environments cared for by family and/or staff who know them.

Increased advance care planning with “person responsible” on admission to residential care, if not already in place, will
assist in determining under what conditions a resident in a RACF should be admitted to acute care and those conditions in which they could be better managed in the facility. These initiatives may help to avoid distressing interventions for people in end stages of dementia.

**Outcomes**

- Carers and service providers are alert to physical health issues, increased confusion, deterioration and/or behavioural changes in the person with dementia.
- A person with dementia has quick access to a medical assessment when required, including assessment of delirium.
- Medical treatment is provided where the person lives if appropriate. Any advance care planning is adhered to.
- If a person needs to be admitted to hospital, the time spent in ED is minimised, he or she is transferred to the appropriate ward and further bed moves are also minimised, where possible.
- People whose dementia will affect their treatment and recovery have access to timely specialist aged health care input. This includes prevention, recognition and management of delirium.
- A person with dementia can be admitted to a specialised behavioural unit in the hospital if he/she has severe behavioural symptoms related to delirium and/or dementia.
- Undiagnosed dementia is identified and referred for assessment and follow up.
- Staff take time to understand the person and their care needs and consult the carer as a partner in care.
- The physical environment has unobtrusive safety features, a variety of spaces including single rooms with good visual access for patients and staff. Noise and clutter is reduced and the environment provides manageable degrees of choice.
- CALD and Aboriginal people experience culturally sensitive treatment and care in a friendly environment.
- The person with dementia has access to a time-limited period of low intensive goal-orientated therapy following an acute episode (Transition care).
- A person with dementia and his or her carer have access to services that are culturally appropriate and can provide timely support on discharge.
- On admission and discharge there is good communication with the person’s GP, community services and the residential care facility if that is where s/he resides.

**Requirements**

1. Community health staff monitor general health and are alert to possible acute illness, delirium or medication issues.
2. Hospital staff trained and supported in culturally and age appropriate person-centred dementia care.
3. Alternative models to inpatient care are available for people with dementia.
4. Routine cognitive screening (for dementia/delirium) of older and/or confused persons on presentation to hospital (whether in Emergency Department (ED) or in wards).
5. Implementation of clinical procedures and pathways for management of delirium.
6. Communication regarding advance care planning occurs between hospitals and residential care facilities and/or families (if transfer is from home).
7. Access to multidisciplinary acute aged care or shared care arrangements, when required.
8. General medical/surgical or geriatric wards designed to be suitable for people with cognitive impairment, including delirium.
9. Effective communication between hospitals, GPs, community services, residential care facilities and other relevant stakeholders.
10. Any worsening confusion immediately assessed.
11. Procedures for chemical and mechanical restraint avoidance in place.
12. Access to specialised behavioural support unit in hospital.
13. Effective collaboration between Aged Health Care and Specialist Mental Health Services for Older People.
15. Access to sub-acute and post-acute care services for people with dementia.
Examples of existing good practice

There are numerous good practice examples in hospital care. While some are not dementia-specific, people with dementia benefit from these initiatives.

A hospital volunteer program to improve the care of patients with dementia

A collaboration between Greater Southern AHS Eastern Sector Dementia Delirium CNC and Dementia Advisor with AANSW Dementia and Memory Service based in Bega aimed to improve the emotional and psychological wellbeing for patients with dementia and/or delirium and reduce their risk of adverse outcomes. Following training in person-centred dementia care, volunteers provide one-to-one support and facilitate group interaction activities for patients with cognitive impairment, targeting peak busy times during the day (8am – 12.30pm and 3pm – 7pm). Volunteers assist with strategies for managing and preventing delirium by providing regular orientation, assisting with meals, encouraging fluids, encouraging gentle exercises and mobilisation and ensuring the wearing of visual and hearing aids. The research report written by Cath Bateman indicates that a person centred care volunteer program model can improve the emotional security, support and quality of care for patients with cognitive impairment.

Integrated aged care services

- Sutherland Hospital Aged Care Services – GMCT Newsletter (Dec 2009 page 18).

Alternatives to inpatient care

- Hospital in the Home/Community Acute/Post-acute Care (HITH/CAPAC) - selected types of acute/post-acute care are delivered as an alternative to inpatient (hospital) care – aim is to avoid hospital admissions or reduce patient length of stay through the immediate provision of multidisciplinary care. In the Acute Post Acute Care (APAC)/GP Shared Care model the GP and the APAC team work closely together to manage the patient in the community.
- Mobile acute care team in Brisbane that visits residential care facilities – Spiritus.

Access to geriatricians and multidisciplinary care team

- The Older Person’s Evaluation Review and Assessment (OPERA) program at Westmead Hospital.
- In rural/remote areas, use of telemedicine for online assessment.

Positions/policies to improve older people’s journey through and experiences in acute care

- 12 Dementia/Delirium CNC positions across NSW funded under the NSW Dementia Action Plan 07-09.
- Emergency Department Aged Care Services in Emergency Teams (ASETs) are multi-disciplinary teams that are skilled in accessing and facilitating care for older people.
- Acute to Age Related Care Services (AARCS).
- 35 Aboriginal hospital liaison officers in NSW hospitals.
- Poole’s Algorithm – General guidelines for the management of disturbed behaviour in older people that accounts for aggression, delirium, depression or other mental disorders and dementia with a plan for ongoing communication and supportive care.
- Care coordination policy – pending.
- NSW Health Avoidance of Mechanical Restraint for Older People Policy Directive – pending.

Medical assessment units

- MAU for non critical and complex patients to reduce their length of stay in ED and improve hospital experience – provides alternative pathway with short term (48 hours) assessment and treatment.

Services post hospitalisation

- COMPACKS (Community packages) – short term support for people transferred from NSW public hospitals who require case management and support services for safe transfer home.
- The Transitional Aged Care Program in NSW for people ACAT assessed as eligible provides short-term care that seeks to optimise the functioning and independence of older people after a hospital stay. Transition care is goal-oriented, time-limited and therapy-focussed.

Carers as partners in care

- Mechanisms for documenting information from carers on how to care for person with cognitive impairment:
  - Top 5 from Carer Support Unit Central Coast, Northern Sydney Central Coast AHS, and
  - The Communication and Care Cue (CCC) Forms from RNS Hospital.
Actions

5.1 Increase community dementia CNC positions to provide clinical advice, consultation, professional support and education to others such as generic health workers in the community so that they monitor health and are alert to possible acute illness, delirium or medication issues that may precipitate a hospital admission.

5.2 Increase dementia/delirium CNC/NP positions in hospitals.

5.3 Increase Aboriginal Liaison Officers in NSW hospitals responsive to local community needs and provide dementia training.

5.4 Provide cultural education programs specific to CALD and Aboriginal people/communities for all hospital staff.

5.5 Consult carers and support them when they choose to be involved in the person’s care.

5.6 Develop and enhance acute residential care clinical support services such as a Nurse Practitioner ED outreach model to assist GPs and RACF staff to provide care within the person’s usual environment and avoid unnecessary admissions.

5.7 Expand alternative models to inpatient care that can deliver services (acute, sub acute and post acute) where the person lives so that routines and familiar support can be maintained.

5.8 Develop and implement a system (based upon known risk factors) for identification of individuals requiring cognitive assessment preoperatively, within ED or on admission to hospital that leads to improved assessment and care planning.

5.9 Develop and roll out a training package to relevant staff regarding the recognition and management of delirium and the use of the Confusion Assessment Method.

5.10 Through enhancement of existing programs, increase the percentage of people with dementia seen in a timely manner by specialist aged health staff when required.

5.11 Increase coverage of Medical Assessment Units in hospitals.

5.12 Develop agreed pathways of care for individuals with cognitive impairment through ED, acute and sub-acute care for all hospitals. Assess basic needs such as feeding and allocate responsibility.

5.13 Include in health facility design guidelines requirements for all non-paediatric wards, including medical and surgical wards, that design to be suitable for people with (acute or chronic) cognitive impairment.

5.14 Promote sector level planning and networks that inform and improve linkages for transition to and from hospitals.

5.15 Explore process between NSW Health and the Guardianship Tribunal that support timely Guardianship applications and Guardianship Tribunal responses to improve transfer of care.

5.16 Implement National Delirium Guidelines and Pathway.

5.17 Issue a NSW restraint avoidance policy directive.

5.18 Progressively develop purpose built inpatient acute behavioural units for people with delirium/dementia and behavioural difficulties.

5.19 Identify and promote the benefits of the NSW Transitional Aged Care Program for people with dementia.

5.20 Increase access to specialist support or shared care models for sub-acute and post-acute services.
The progressive nature of dementia, the loss of functioning in daily living skills and the accompanying BPSD and the subsequent burden on carers often leads to entry into residential care. The decision and adjustment to residential care can be very difficult for families and carers, especially spouses. Most residents of RACFs have dementia and over half are aged over 85 years.

There are general issues surrounding residential care in NSW including funding and viability issues, attracting and retaining staff, limited registered nursing care, residents losing their previous GP and accessing medical care with geriatric knowledge.

On a broader level, Australia’s current models of residential care are being questioned. New supported accommodation models are being developed for people as they age that allow older people to remain where they choose to live with access to care as required. The Apartments for Life model90 currently being implemented in Waverley is an example based on the Humanitas model in the Netherlands. In Japan, the community mutual support model is based on sharing “an ordinary life” with people with dementia.

NSW Health has worked in partnership with the DoHA and individual residential aged care providers to pilot small units within larger residential aged care facilities that provide increased supports for an interim period for individuals unable to be managed in mainstream facilities due to behavioural disturbance. These complement specialist inpatient services. An evaluation is currently being finalised.

There are aged care providers that are redesigning their residential care services to be more supportive of people with dementia, both in physical environment and in care practices. While the following does not apply to all residential aged care facilities, reported issues include:

- High rates of BPSD with limited access to specialised support, unable to manage residents with very severe BPSD.
- Few dementia specific units for active and mobile residents, particularly those with YOD with secure, appropriate environments and care.
- Environmental designs that are not conducive to person-centred care.
- Difficulties in mixing the frail aged and people with dementia who are mobile.
- Misuse of psychotropic medications.
- Lack of compliance with law about psychotropic prescribing for persons unable to give informed consent91 (which is likely to be an issue in hospitals too).
- Lack of dementia-specific staff training.
- Variable integration of families in care of people with dementia.
- Variable standard of recognition of physical illness and pain.
- Few appropriate options for people with YOD and Aboriginal people.
- Social isolation of people from CALD backgrounds in mainstream care with no one speaking their language. Staff may also be from different CALD backgrounds. BPSD may arise from cultural misunderstandings between staff and residents.
- People in rural and remote areas can be located some distance away from their previous community.
- Staff in prisons may not have aged care/dementia care expertise and it can be difficult to access residential aged care.
- The impact of transition on carers, the abrupt ending of support services and their experience of guilt and grief.

In considering residential care for Aboriginal people, DoHA uses an age criteria of 50 years and over for planning aged care services (residential care, CACP, EACH and EACH-D) for Aboriginal and Torres Strait Islander people. It must be acknowledged that Aboriginal people are closely connected to their land and to family. Moving away is distressing for Aboriginal people and their families who often face transport issues. Entry into residential care is viewed as the last resort. Importantly, if Aboriginal people are experiencing residential respite as a positive experience, others may be willing to try it.
Outcomes

- A person with dementia resides in a facility that has strong professional leadership, striving to meet high quality care such as outlined in the Quality Care Standards developed by AA.
- A person with dementia receives culturally and age appropriate person-centred care by staff trained in dementia and palliative care.
- People with BPSD are assessed and appropriately managed.
- The facility is home like, with unobtrusive safety features, a variety of spaces including single rooms with good visual access for residents and staff. Noise and clutter is reduced and the environment provides manageable degrees of choice.
- A resident has access to appropriate and timely health care.
- Carers receive ongoing support during transition and while a person is in residential care and are offered counselling to deal with guilt and grief.
- Carers are consulted and included in care.
- A person in early dementia has appointed an Enduring POA, an Enduring Guardian, completed an advance care directive or has discussed their future preferences for health care treatment with family/GP and this has been documented in the resident’s file in the facility. If not, he/she is supported to do so.
- Persons with dementia, their legally recognised Person Responsible, their GP and relevant care staff discuss possible future care issues and the person’s care/treatment preferences.

Requirements

1. Local facilities that are able to provide accessible quality care for people with dementia with a range of diverse needs.
2. Safe, Dementia-friendly environment that supports person-centred care, provides sufficient privacy and space for socialisation and provides a range of appropriate activities.
3. Carer support during transition and while a person is in residential care.
4. Access to primary health care with dementia care knowledge – GPs/practice nurses, NPs, CNCs and CNSs trained in dementia care.
5. Strong partnerships between RACFs, GPs and aged health services to avoid unnecessary admissions.
6. Well trained and supported staff.
**Examples of existing good practice**

- **Positive Living in Aged Care (PLAC) Awards** recognise residential aged care providers in NSW who are implementing strategies to promote a positive approach to the prevention and management of mental health conditions.
- **Starrett Lodge** has redesigned its environment and changed care practice through the introduction of an intergenerational program.
- **Support Groups for family carers of residents.**
- **Hornsby Ku-ring-gai Hospital Service (HKHS)** has developed the **Geriatric Rapid Acute Care Evaluation (GRACE)** model of care to improve the health care journey of aged care residents.
- **Inspire Me DVD** provides a guide on how to assess, plan, facilitate, evaluate and document person-centred activities for people living with dementia in community and residential settings.
- **HammondCare** offers permanent and respite residential services specifically for YOD at HammondCare Horsley.
- HammondCare and Catholic Health Care special care programs for individuals with behavioural disturbance unable to be managed in mainstream, residential facilities, delivered in partnership with NSW Health.
- The use of **environmental assessment tools** for the evaluation of residential aged care facilities for people with dementia.
- **Rose Mumbler Aboriginal Village** has low level care and also delivers CACPS.
- South East Sydney Illawarra AHS has developed a **resource folder to assist RACFs to implement and improve ACP practices.**
- North Coast AHS provides a NP ED outreach service to RACFs with the aim of avoiding hospital admission and treatment in RACFs.

**Actions**

6.1 Encourage and support facilities to develop high quality care such as outlined in Quality Care Standards developed by AA.
6.2 Promote and implement evidence based dementia design.
6.3 Provide support to carers during transition and while a person is in residential care.
6.4 Provide incentives for GPs/practice nurses to develop dementia care knowledge. Increase residential aged care access to NPs, CNCs and CNSs trained in dementia care.
6.5 Develop acute residential care clinical support services, including after hours, to assist GPs and RACF staff to provide care within the person’s usual environment and avoid unnecessary admissions.
6.6 Implement strategies to attract, retain and support staff in RACFs.
6.7 Provide cultural competency training to residential staff.
Over 90 percent of people with dementia experience BPSD during the course of their illness\(^\text{92}\) (20 percent moderate, 10 percent severe). BPSD include:

- mild symptoms such as apathy, mild depression and repetitive questioning;
- moderate symptoms such as major depression, verbal aggression, low level physical aggression, psychosis, sexual disinhibition and wandering;
- severe symptoms such as severe depression, aggression and marked agitation; and
- very severe symptoms that include superimposed delirium, acute psychiatric problems and dangerous physical aggression.

BPSD are intrinsic to dementia but can be improved or worsened by the environment, by interactions with others, by the care provided or by treatment (pharmacological and non-pharmacological). For example, residential respite for men may lack male orientated activities leading to a deterioration of behaviour and increase in psychotropic medication. Communication issues with people from CALD backgrounds can increase fear and frustration and lead to agitation or aggression. Antipsychotic drugs are often used, frequently with minimal benefit and with the potential risk of serious adverse effects. Behaviours are generally time limited but can persist for one or two years. For example, a study following people with Alzheimer’s disease found that agitation persisted for a two-year period.\(^\text{93}\)

BPSD is common in YOD, particularly due to the types of prevalent frontotemporal dementia. Behavioural symptoms are also often a presenting symptom in YOD.\(^\text{94}\)

\[“\text{The staff seemed to think his behaviour was his fault, that he was being difficult on purpose” – carer.}\]

BPSD have an enormous impact on individuals, carers, health, community care and residential aged care systems. They are associated with lower function, poorer prognosis, increased burden on family carers and nursing home staff, higher costs of care and earlier institutionalisation.\(^\text{92}\) BPSD can prevent carers receiving respite when they need it the most.

\[“\text{I need help to know how to be with him not just what to do for him.” – carer.}\]

The management of BPSD has historically been plagued by boundary issues between mental health and aged care and between Commonwealth and States. There has been expansion of services to support carers and health professionals, community care workers and residential care staff in the management of BPSD such as the NSW funded BASIS, and the Commonwealth funded DBMAS programs. However, coverage is still limited.

EACH–D packages, also limited, provide a case management service that specifically targets BPSD and can provide a range of flexible support services.

Behaviours may be severe, requiring admission to a transitional assessment and treatment unit. However, there is currently limited coverage across NSW. Some people with very severe or extreme behaviours who cannot be managed in the community or in residential care require access to specialist intensive care units until behaviours subside and they can return to mainstream residential care.

The following diagram\(^\text{9}\) provides a planning model for the management of BPSD,\(^\text{92}\) noting that there is good quality evidence supporting the effectiveness of interventions outlined in Tiers 3, 4 and 5. For example, culturally appropriate psycho-education of carers, including CALD and Aboriginal people, in problem solving and behavioural interventions can decrease agitation and anxiety in persons with dementia\(^\text{95}\) and collaborative primary care can improve BPSD.\(^\text{63}\) A person-centred approach with an emphasis on respect and dignity, effective communication and involvement of carers can reduce agitation in residential care.\(^\text{96}\)

\(^\text{9}\) ©Copyright 2003. The Medical Journal of Australia – reproduced with permission
Figure 6. Seven-tiered model of management of behavioural and psychological symptoms of dementia.\(^9\)2

*Prevalence is expressed as estimated percentage of people with dementia who currently fall into this category.
†Estimate based on clinical observations.
‡Estimate based on Lyketsos et al.\(^6\)

**Outcomes**

- Carers, GPs, community care, community health, hospital and residential care staff and volunteers, are trained in culturally and age appropriate person-centred care, assessment and non-pharmacological and pharmacological management of BPSD. They have access to specialised advice and treatment when required.
- A person’s physical health is monitored and carers, GPs and other health and community care staff are alert to the possibility of delirium if confusion worsens or behaviour changes.
- A person with dementia who is experiencing BPSD is comprehensively assessed to identify a range of possible internal and external causes and to develop multi-level interventions that are implemented by supported staff.
- People with dementia in hospital or residential care are in dementia-friendly environments - home like, with unobtrusive safety features, a variety of spaces including single rooms with good visual access for residents and staff. Noise and clutter are reduced and the environment provides manageable degrees of choice. Mechanical and chemical restraint is avoided.
- If medications are used they are regularly reviewed and closely monitored. Prescribers comply with laws regarding obtaining substitute consent.
- If people with dementia have severe BPSD and cannot be cared for at home or in residential care they have access to short and longer-term specialist care units in inpatient and community settings.

**Requirements**

1. Provision of culturally appropriate education on person-centred care and management of BPSD to carers, GPs, community care, community health, hospital and residential care staff and volunteers.
2. Provision of services that provide support, information and specialist advice to workers and carers where a person is living.
3. Access to sub-acute/non-acute transitional assessment and treatment units for people with dementia and severe BPSD eg T-BASIS.
4. Access to specialised intensive care units for people with very severe BPSD.
5. Access to SMHSOP with strong partnerships with aged health services.
6. Access to a local residential care facility that can cater for people with severe BPSD.
Examples of existing good practice

- Warrigal Care in Goulburn was a finalist in the 2008-09 PLAC awards for Validation, Recognition and Calming of Residents with Dementia.
- The DBMAS in North Sydney Central Coast AHS has run a group clinical supervision program with facilities to strengthen person-centred care for clients with moderate to severe BPSD. It will be the subject of a research study during 2010 though the anecdotal evidence from three trials includes improved problem solving and reduced incidents of aggression.
- Strong partnerships - POWH between SMHSOP (including 0.5 FTE BASIS position), aged care and community nurses and Fairfield-Liverpool where aged care and SMHSOP developed a local service agreement. In Fairfield-Liverpool BASIS functions are integrated into a community SMHSOP Team that liaises closely with ACAT. The sub-acute SMHSOP inpatient unit admits patients with severe BPSD from both acute geriatric and mental health units or after community team involvement.
- The weekly Chronic Disease Clinic run at La Perouse Aboriginal Community Health Centre is conducted with Aboriginal health education officers in attendance, by a geriatrician who has expertise in dementia diagnosis and, as required, access to pathways for referral to the local Cognitive Disorders Clinic for further assessment; ongoing referral to the Dementia CNC and CDN team for further management and support; and for referral to Aboriginal specific home care and respite services.
- 180 clinicians participated in a recent SMHSOP training workshop focusing on person-centred care for people with dementia and BPSD.

Actions

7.1 Expand positions that provide advice and education on person-centred care and management of BPSD in community, acute and residential care.

7.2 Continue to implement the SMHSOP Service Plan, including:

7.2a Expand community based BASIS and DBMAS programs for people with moderate and severe BPSD and carers.

7.2b Develop and expand sub-acute/non-acute transitional assessment and treatment units for severe BPSD.

7.2c Establish specialist intensive care units for very severe BPSD.

7.3 Develop clearly defined roles for SMHSOP and aged health services for all community and hospital networks with mechanisms for review and resolution of any role disputes at clinical or service level. Develop effective governance systems to facilitate the above.

7.4 Further develop specialist programs/units within RACFs for people with severe behavioural disturbance.
Palliative care for people with dementia is active, person-centred care which provides relief of symptoms experienced towards the end of life and support to family and carers during this time. A palliative approach focuses on quality of life, the relief of suffering and ensuring that the person is as comfortable as possible. It can take place in any setting.

The usual dementia trajectory is a gentle decline over a long period with the person becoming increasingly dependent. Knowing exactly when death will occur is difficult. By the time people are in an advanced stage of dementia they are usually in residential care. People with advanced dementia often do not receive adequate or appropriate end-of-life care. Pain is significantly under-diagnosed and undertreated.

The DCRC for carers and consumers based at QUT undertook a systematic review of the effectiveness and appropriateness of a palliative approach to care for people with advanced dementia. The review found:

- No evidence to support the use of complex, life-prolonging treatments for persons with dementia;
- Feeding tubes were not an effective method of providing nutrition for people with advanced dementia and can increase suffering, nor was the use of intravenous antibiotics helpful in the long term;
- Admission to hospital at the end of life did not improve quality of life;
- Strategies designed to treat the unpleasant symptoms of advanced dementia (such as pain and agitation) and improve quality of life were most beneficial to patients;
- The mental and physical decline experienced by people with dementia may continue over many years and each patient’s path may vary but it is important that families and significant others understand that the decline into death is inevitable and plan accordingly; and
- Good quality end-of-life care for people with advanced dementia accepts that the goal of care is to promote quality of life and allow a dignified natural death.

The Clinical Course of Advanced Dementia notes that dementia is under-recognised as a progressive, terminal illness. Pneumonia, febrile episodes and eating problems are frequent in advanced dementia and are associated with high, six monthly mortality rates. Distressing symptoms increase towards end of life and burdensome interventions are common, though it was noted there is less aggressive care when health proxies (or in NSW terminology, Persons Responsible) were aware of poor prognosis and expected clinical complications.

Three triggers for palliative care have been suggested:

- The surprise question ‘Would you be surprised if this patient were to die in the next 6-12 months?’;
- Choice/ Need - The person with advanced disease (their guardian or Person Responsible) makes a choice for comfort care only, not ‘curative’ treatment, or is in special need of supportive palliative care; and
- Clinical indicators - Specific indicators of advanced dementia.

Advance care planning is a crucial aspect of person-centred care. Ideally people have the opportunity to communicate their wishes in advance while they still have capacity. Well planned and managed family conferences, and documentation can importantly remove the conflict that may arise when carers, families and health professionals must make these decisions in the absence of this knowledge and allow for appropriate management based on a person’s wishes, values and beliefs about medical treatment and end of life preferences.

Advance care planning combined with collaboration between hospitals and residential aged care facilities significantly improve outcomes for residents. However, there is currently poor uptake of advance care planning.

Non complex palliative and end of life care for persons with end stage dementia can be provided by primary care teams and general services.

Currently there are differing views and practices concerning the eligibility of people with dementia to specialist palliative care services, the reach of specialist palliative care into residential care and whether they have the expertise in dementia care.
In NSW the *NSW Palliative Care Strategic Framework 2010 – 2013* will advance the implementation of the *Role Delineation Framework* that will clarify the role of specialist palliative care services, when a shared care model is needed and how to strengthen general services to provide palliative care. When caring for someone dying at home, families need to know that they are providing the right care and what to do in the event of an emergency. They need timely professional support and back up when requested.

### Outcomes

- Family members have the opportunity to discuss advanced stage of dementia and end-of-life issues including evidence based information on nutrition, pain management and hydration, with GP, facility staff and other health professionals in a manner that is culturally sensitive. If the person is in hospital, staff also provide the opportunity.
- If an Enduring Guardianship has not been appointed, the legal substitute decision maker (Person Responsible) completes a plan of care based on what they believe the resident's wishes would be. The plan of care can determine what conditions the resident should be admitted to acute care and in which they could be managed in the facility.
- Staff are aware of and respect a person and family's beliefs and practices regarding illness, death and bereavement. For example, an Aboriginal person's wish to return home to die is respected. At the same time, staff do not assume practices based on ethnicity.
- Staff are trained in and implement palliative care principles and have access to Specialist Palliative Care Services if required.
- A person's comfort is maintained and infections or symptoms such as pain are well managed. A person is not routinely tube fed when they can no longer swallow. Evidence based information is provided to carers, families and others, such as volunteer supporters.
- Carers experiencing anticipatory grief or bereavement are appropriately supported leading up to and after the death.
- When caring for someone dying at home, carers and families know that they are providing the right care and what to do in the event of unexpected changes. They have access to timely professional support and back up when requested.

### Requirements

1. A palliative care approach adopted for people with advanced dementia and access to specialist palliative care when required.
2. Plan of care discussed with person with dementia and/or Person Responsible, their GP and relevant care staff, documented and implemented.
3. Family case conferences and information on advanced stage of dementia provided.
4. Staff training in palliative care and advance care planning.
5. Counselling and bereavement support for carers.
Examples of existing good practice


- Staff training in residential care - In 2005-2006 Palliative Care Australia (PCA) was funded by DoHA to undertake the project *Introducing the Guidelines to a Palliative Approach in Residential Aged Care* to raise awareness of the Guidelines. Training Resources have been produced as part of that project. Modules include:
  - Pain assessment and management,
  - Symptom management,
  - End of life care,
  - Support of and communication with the family,
  - Grief and bereavement support, and
  - Advance care planning.

- **South East Sydney AHS project** - education of residents, families, residential care staff and GPs about outcomes of dementia, advance care planning and a hospital outreach service to residential facilities resulted in decreased hospital admission and decreased mortality for residents.

- The NSW Health Advance Care Planning Model of Care provides a summary of the key characteristics of ACP, the elements of success, how it works in different settings, the process and the staff skills required. There are ACP policies, literature, tools and templates for health professionals to support ACP implementation.

- NSW Health is implementing ACP across NSW. AHSs deliver ACP training and education to GPs, RACF staff and to members of the public. An e-learning package is in development for the ongoing education and training of NSW Health staff. A dementia specific resource on ACP for the substitute decision makers of those who have lost capacity will be available to the public, RACFs, community groups and NSW Health services.

- A report on the evaluation of the *National Implementation of the Respecting Patient Choices Program* found that if a person’s end-of-life are discussed in a sensitive and supportive manner and documented clearly and consistently within and between service sectors then people receive health care in the place of their choice, avoiding unwanted and often burdensome treatments.

- A green booklet, *Dementia information for carers, families and friends of people with severe and end stage dementia*, was produced as a result of the Palliative Care Dementia Interface Enhancing Community Capacity Project.

- A *Plan of Care* book on how to make health and personal care decisions for a person who has dementia and lost their capacity to make their own decision.

- **CareSearch**, an online resource of palliative care information and evidence.

- Providing culturally appropriate palliative care: *Aboriginal and Torres Strait Islander Resource Kit Project*. 
Actions

8.1 Continue to implement the *Guidelines for a Palliative Approach in Residential Aged Care*, including culturally sensitive palliative care training for residential care staff.

8.2 Support the implementation of good practice examples that result from the Dementia Palliative Care Projects funded under Round five of the National Palliative Care Program. Promote evidence based resources developed.

8.3 Identify and support the use of best practice models for pain assessment and management for persons with dementia across all settings.

8.4 Clarify the role of AHSs specialist palliative services in dementia in acute, residential and community care.

8.5 Implement initiatives to increase community awareness of ACP.

8.6 Discuss ACP and document on admission to residential care.

8.7 Conduct family case conferences and provide culturally sensitive information on advanced dementia.

8.8 Provide training for relevant health and community care staff on ACP and their responsibilities, advanced dementia and end of life care, including the use of non-verbal observational validated pain assessment tools.

8.9 Increase access to counselling and bereavement support for carers when required.
Enablers

The previous section outlined for each stage of the service pathway the specific drivers for change, desired outcomes, key requirements, examples of good practice and actions. However, there are some key requirements and recommendations for action that span across the dementia service pathway that have been identified as key enablers. These include:

1. Funding
   - Develop clear and transparent funding structures for health, community care and residential aged care that can provide a sustainable base for improving current services and for responding to increasing demand in the future.

2. Planning
   - Develop and implement a dementia population planning model similar to the Mental Health Clinical Care and Prevention Model to quantify resources required along the dementia service pathway.
   - Undertaking integrated dementia planning at a network level, including rural areas.

3. Executive and senior management commitment
   - Include clear expectations and commitment of executive and senior management in the implementation plan for the NSW Dementia Services Framework 2010-2015.

4. Policy development
   - Develop pathways regarding assessment, diagnosis, care and case management of people with dementia. These should outline the role for relevant parties, including GPs, practice nurses, dementia experts within aged health services, BPSD experts in mental health teams and community care case managers; and refer to relevant Australian and international guidelines.
   - Develop recommended standards in specific areas, the resources required to implement standards outlined, including resourcing flexible, viable models for rural and remote areas and for specific communities.

5. Service co-ordination
   - Based on Enabler 2, develop networks of coordinated services across NSW. Maintain and enhance linkages between primary care, national aged care services (in the future to include CRCCs, ACATs, HACC, Packaged Care Providers and Residential Aged Care Providers), jointly funded services such as TACP, state specialist health services (aged health services, SMHSOP, severe chronic disease management, palliative care) and state community care and disability services.
   - Expand coverage of DASs so that they can take a lead in network dementia planning and service coordination across health, community care and residential care services. This includes maintaining updated information on services and eligibility, establishing and maintaining networks, establishing and promoting agreed referral protocols, organising carer support groups and carer education, and addressing outreach/access issues.

6. Education, training and workforce development
   - Provide dementia and delirium training for health, community care providers, and dementia specialists across all settings across the dementia service pathway, including accessible training for rural areas.
   - Include in residential staff training the elements of high quality care such as outlined in Quality Care Standards developed by AA.
   - Include dementia training in the training of relevant frontline staff in preparation for increasing dementia prevalence and demand for support.
   - Provide cultural competence training for health, community and residential care providers across all settings that is relevant to local needs.
   - Negotiate appropriate dementia-related content in the undergraduate training of all health professionals.
   - Include dementia and delirium in the common core elements developed by the Clinical Education and Training Institute.
Develop systems of credentialing of expertise relevant to dementia care within NSW Health and ADHC to encourage recruitment, skill development and career pathways.

Implement Health Workforce Reform through Health Workforce Australia and other principal committees where appropriate, including workforce strategies to attract, recruit and retain positions and lift profile and importance of aged care as a specialty.

7. Development of an evidence base and service data

- Improve dementia specific data collection across the service pathway.
- Develop models of care based on research and evaluation evidence that include benchmarks for quality dementia care.
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### Framework - Key requirements and actions for each stage of the service pathway *

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<th>Key requirements</th>
<th>Action</th>
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<tbody>
<tr>
<td><strong>1. The public are provided with positive messages about dementia, that there are interventions that can make a difference and to see their GP if concerned.</strong></td>
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<td><strong>1.1 Conduct market research to identify barriers/enablers to seeking help with memory loss.</strong></td>
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<td><strong>1.1.2 Develop and implement an evidence based, positive national dementia awareness campaign.</strong></td>
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<td><strong>1.1.3 Promote “planning ahead” - Enduring POA, Enduring Guardianship and advance care planning.</strong></td>
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<td></td>
<td><strong>1.1.4 Develop partnerships with service providers for specific population groups to promote awareness of dementia, dementia risk factors and “planning ahead” within these communities, and to develop and/or distribute information resources in consultation with communities.</strong></td>
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<tr>
<td><strong>1.2 Implementation of positive, local awareness strategies in specific population groups.</strong></td>
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<td><strong>1.2.1 Develop action 1.1.4 as a key role for DASs in partnership with HACC development officers, Aboriginal Access workers and Multicultural Access Project workers.</strong></td>
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<td><strong>1.2.2 Build DAS network so that consistent, culturally and age appropriate, evidence based messages are promoted.</strong></td>
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<td><strong>1.3 Further research to understand the interaction between risk factors and dementia, and effectiveness of interventions.</strong></td>
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<td><strong>1.3.1 Continue research investment into risk reduction through the wider research agenda (NHMRC) and through specific DCRC funding.</strong></td>
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<td><strong>1.4 Incorporation of dementia risk reduction messages into existing public health and health promotion strategies and campaigns.</strong></td>
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<td><strong>1.4.1 Develop and implement strategies based on research (action 1.3.1), and on the evaluation of the NSW Health Dementia Risk Reduction Awareness campaign and parallel GP Project to be conducted in the Shoalhaven and Illawarra regions focusing on the link between hypertension and dementia in the 45 years and over age group.</strong></td>
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<tr>
<td><strong>1.5 Inclusion of risk reduction into GPs, other primary care professionals, as well as specialist aged health services, and the NSW Transitional Aged Care Program’s communication with patients/clients.</strong></td>
<td></td>
<td><strong>1.5.1 Educate GPs and other primary care professionals and community care staff regarding dementia, dementia risk reduction, planning ahead and legal requirements for informed consent. Include in medical, nursing and allied health student education.</strong></td>
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<td></td>
<td><strong>1.5.2 Negotiate the inclusion of dementia risk reduction in the existing Aboriginal Chronic Disease Program. Link to local Aboriginal Medical Services (eg as done with diabetes education).</strong></td>
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<td><strong>1.6 Identification and support for people most at risk to achieve lifestyle changes, including availability of physical activity programs for older people.</strong></td>
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<td><strong>1.6.1 Link to healthy lifestyle initiatives. Increase availability of and access to physical activity programs for older people, such as Active Over 50 and Heartmoves.</strong></td>
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<tr>
<td><strong>1.7 Implementation of health and education early intervention programs across the life span that reduce disadvantage and optimise cognitive development.</strong></td>
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<td><strong>1.7.1 Continue to implement early intervention programs that target vulnerable families.</strong></td>
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<td><strong>1.7.2 Continue to implement the National Partnership Agreement on Preventative Health and the National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes.</strong></td>
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</table>

*Order for listing of actions within each stage of dementia service pathway does not imply priority.*
### 2. Assessment, Diagnosis and Ongoing Management

<table>
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<tr>
<th>Key requirements</th>
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<tr>
<td><strong>2.1</strong> Referral protocols are agreed to at a network level and promoted.</td>
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<tr>
<td><strong>2.1.1</strong> Promote diagnosis and assessment referral protocols to key health services (GPs/practice nurses, AMSs, Medicare Locals, Hospital Networks, pharmacies, etc.) and to community service contact points such as CRCC and proposed One Stop Shops.</td>
</tr>
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| **2.2** GPs, AMSs and/or their practice nurses respond to concerns, carry out investigations, diagnose or if preferred, refer to a dementia expert for diagnosis & are involved in the ongoing care plan in an integrated care model. |
| **2.2.1** Provide GP/practice nurses and AMSs with training opportunities and incentives to undertake dementia assessment, diagnosis and ongoing management. Include guidelines, screening instruments and referral forms in software used by GPs. Adequately remunerate GPs for time spent in assessment, carer consultation, diagnosis, information, referral and joint care planning. |

| **2.3** Integrated care models between GPs and aged health services resourced to include dementia health experts such as community dementia nursing and allied health positions for a comprehensive assessment and consultation with specialists such as geriatricians if diagnosis is unusual or difficult, or psychogeriatricians for psychotic or severe behavioural issues. |
| **2.3/2.4.1** Develop integrated models between GPs, AMSs and specialist memory assessment and review teams (SMART), involving specialist community dementia nursing (CDNs, CNSs, CNCs, NPs) and allied health positions and access to appropriate specialist doctors. |

| **2.4** Dementia experts trained in diagnosis and culturally sensitive comprehensive assessment are accessible in a timely manner. They work with Aboriginal health and CALD liaison officers. |
| **2.3/2.4.2** Quantify resources for equitable access to specialist services in the dementia population planning model that includes viable models for rural and remote areas, such as NP models, and that addresses the needs of specific populations. |

| **2.5** A key worker with a health qualification, skilled in dementia who works closely with the person's GP/AMS proactively follows up after diagnosis and builds a continuing relationship. The key worker case manages care needs as they increase and/or become complex |
| **2.5.1** Increase coverage of key workers. Include key worker in dementia population planning model. |

| **2.6** Generic health and community care workers, including Transitional Aged Care workers are trained to recognise symptoms of possible cognitive impairment, consult experts and refer (with consent). |
| **2.6.1** Provide and promote dementia training opportunities for generic health and community care workers. |

| **2.7** Professionals are trained in the appropriate use of screening tools to improve competency and interpretation. |
| **2.7.1** Develop evidence based guidelines for targeted assessment to detect dementia and train health professionals in the appropriate use of assessment tools. |

| **2.8** GPs and health staff trained in advance care planning and knowledge of the legal requirements. |
| **2.8.1** See 1.5.1 |
### 3. Information, Counselling & Carer Education

<table>
<thead>
<tr>
<th>Key requirements</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1 Dementia expert to provide information following diagnosis at clinic and/or home visit.</td>
<td>3.1/3.2.1 Train and resource GPs/practice nurses to provide or refer for information and support.</td>
</tr>
<tr>
<td>3.2 Proactive follow-up from identified key worker.</td>
<td>3.1/3.2.2 Increase access to a key worker.</td>
</tr>
<tr>
<td>3.3 Culturally and age appropriate written and verbal information provided.</td>
<td>3.1/3.2.3 Provide comprehensive coverage of Dementia Advisory Services with strong links to AANSW.</td>
</tr>
<tr>
<td>3.4 Culturally and age appropriate education and counselling for people with dementia and their carers (ind./group, telephone).</td>
<td>3.4.1 Continue to promote Dementia Helpline 1800 100 500 and counselling services through AANSW.</td>
</tr>
<tr>
<td>3.5 Range of appropriately targeted carer support groups responsive to the diversity of local need – eg Aboriginal, CALD, YOD, male.</td>
<td>3.5.1 Review availability of a range of culturally and age appropriate carer support groups and encourage expansion if required.</td>
</tr>
<tr>
<td>3.6 Carer education sessions.</td>
<td>3.6.1 Expand access to LWML Programs for people in early stages to include people from specific population groups.</td>
</tr>
<tr>
<td>3.7 Accessible, flexible, culturally and age appropriate, person-centred case managed packages of care for people with dementia with complex care needs.</td>
<td>3.6.2 Provide access to and promote a range of carer education sessions.</td>
</tr>
</tbody>
</table>

### 4. Community Support

<table>
<thead>
<tr>
<th>Key requirements</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1 Identified key worker available for family to contact and assist with linking to services.</td>
<td>4.1.1 Clarify the role of DASs and CDNs as key workers.</td>
</tr>
<tr>
<td>4.2 Accessible up-to-date information on local dementia services available and promoted.</td>
<td>4.1.2 Increase coverage of key workers.</td>
</tr>
<tr>
<td>4.3 A well planned, networked and coordinated service system.</td>
<td>4.1.3 Include key workers in the dementia population planning model.</td>
</tr>
<tr>
<td>4.4 Services that can provide a timely and flexible response to diverse and increasing needs.</td>
<td>4.2.1 Include the responsibility for updating dementia service information in the role of DAS that is then promoted through multiple links including existing Commonwealth Respite and Carelink Centres 1800 052 222, Dementia Helpline 1800 100 500 and proposed One Stop Shops, and Medicare Locals.</td>
</tr>
<tr>
<td>4.5 Capacity to support people with dementia to remain for longer with their familiar support service.</td>
<td>4.3.1 Develop a dementia population planning model to guide funding of community support services.</td>
</tr>
<tr>
<td>4.6 A range of accessible, culturally and age appropriate, mainstream community care services, competent in person-centred dementia care available for people with non-complex care needs.</td>
<td>4.3.2 Include quality dementia care in any community care standards developed.</td>
</tr>
<tr>
<td>4.7 A range of accessible, culturally and age appropriate, person-centred dementia-specific services available for people requiring specialised dementia care.</td>
<td>4.3.3 Include the development of Network-level planning and service networks in the role of DASs.</td>
</tr>
<tr>
<td>4.8 Accessible, flexible, culturally and age appropriate, person-centred case managed packages of care for people with dementia with complex care needs.</td>
<td>4.4/4.5.1 Promote the development and implementation of innovative models of care that respond to diverse need of specific population groups.</td>
</tr>
<tr>
<td>4.9 Access to evidence based advice on promoting dignity, independence and implementing safety in the home and other community settings.</td>
<td>4.4/4.5.2 Develop and implement affordable and accessible transport options for people with dementia no longer able to drive to promote social inclusion and access to services.</td>
</tr>
<tr>
<td>4.10 Accessible advice on responding to the abuse of vulnerable adults.</td>
<td>4.4/4.5.3 Evaluate the use of 500 consumer directed care (CDC) flexible care places and 200 consumer directed respite care places for people with dementia.</td>
</tr>
<tr>
<td>4.10.1 Increase access to evidence based advice on promoting dignity, independence and safety through including allied health dementia experts in the dementia population planning model.</td>
<td>4.4/4.5.4 Address the needs and access to services of people with YOD in particular, following the reorganisation of services under the COAG reforms, noting the outcomes of AANSW’s YOD research project.</td>
</tr>
<tr>
<td>4.10.2 Provide access to evidence based assistive technology and support further development of the evidence base.</td>
<td>4.6/4.7/4.8.1 Expand access to culturally and age appropriate support services, the range of respite options and flexible packaged care.</td>
</tr>
<tr>
<td>4.6/4.7/4.8.2 Expand the availability of community support models suitable for people with dementia living alone.</td>
<td>4.6/4.7/4.8.3 Review existing funding and eligibility requirement to enable greater flexibility in service delivery.</td>
</tr>
<tr>
<td>4.6/4.7/4.8.4 Evaluate the use of 500 consumer directed care (CDC) flexible care places and 200 consumer directed respite care places for people with dementia.</td>
<td>4.9.1 Increase access to evidence based advice on promoting dignity, independence and safety through including allied health dementia experts in the dementia population planning model.</td>
</tr>
<tr>
<td>4.9.2 Provide access to evidence based assistive technology and support further development of the evidence base.</td>
<td>4.9.3 Increase access to evidence based advice on promoting dignity, independence and safety through including allied health dementia experts in the dementia population planning model.</td>
</tr>
<tr>
<td>5. Hospital care</td>
<td>Key requirements</td>
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<td>-----------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>5.1 Community health staff monitor general health and are alert to possible acute illness, delirium or medication issues.</td>
<td>5.1.1 Increase community dementia CNC positions to provide clinical advice, consultation, professional support and education to others such as generic health workers in the community so that they monitor health and are alert to possible illness, delirium or medication issues that may precipitate a hospital admission.</td>
</tr>
<tr>
<td>5.2 Hospital staff trained and supported in culturally and age appropriate person-centred dementia care.</td>
<td>5.2.1 Increase dementia/delirium CNC/NP positions in hospitals.</td>
</tr>
<tr>
<td>5.3 Alternative models to inpatient care available for people with dementia.</td>
<td>5.3.1 Develop and enhance acute residential care clinical support services such as a Nurse Practitioner ED outreach model to assist GPs and RACF staff to provide care within the person’s usual environment and avoid unnecessary admissions.</td>
</tr>
<tr>
<td>5.4 Routine cognitive screening (for dementia/delirium) of older and/or confused persons on presentation to hospital (whether in ED or in wards).</td>
<td>5.4/5.5.1 Develop and implement a system (based upon known risk factors) for identification of individuals requiring cognitive assessment preoperatively, within ED or on admission to hospital that leads to improved assessment and care planning.</td>
</tr>
<tr>
<td>5.5 Implementation of clinical procedures and pathways for management of delirium.</td>
<td>5.5.1 Implement National Delirium Guidelines and Pathway.</td>
</tr>
<tr>
<td>5.6 Communication regarding advance care planning occurs between hospitals and residential care facilities and/or families (if transfer is from home).</td>
<td>5.6.1 See next two sections – residential and palliative</td>
</tr>
<tr>
<td>5.7 Access to multidisciplinary acute aged care or shared care arrangements, when required.</td>
<td>5.7.1 Through enhancement of existing programs, increase the percentage of people with dementia seen in a timely manner by aged care specialist staff when required.</td>
</tr>
<tr>
<td>5.8 General medical/surgical or geriatric wards designed to be suitable for people with cognitive impairment, including delirium.</td>
<td>5.8.1 Include in health facility design guidelines requirements for all non-paediatric wards, including medical and surgical wards, and design to be suitable for people with (acute or chronic) cognitive impairment.</td>
</tr>
<tr>
<td>5.9 Effective communication between hospitals, GPs, community services, residential care facilities and other relevant stakeholders.</td>
<td>5.9.1 Promote sector level planning and networks that inform and improve linkages for transition to and from hospitals.</td>
</tr>
<tr>
<td>5.10 Any worsening confusion immediately assessed.</td>
<td>5.10.1 Implement National Delirium Guidelines and Pathway.</td>
</tr>
<tr>
<td>5.11 Procedures for chemical and mechanical restraint avoidance in place.</td>
<td>5.11.1 Issue a NSW restraint avoidance policy directive.</td>
</tr>
<tr>
<td>5.12 Access to specialised behavioural support unit in hospital.</td>
<td>5.12.1 Progressively develop purpose built inpatient acute behavioural units for people with delirium/dementia and behavioural difficulties.</td>
</tr>
<tr>
<td>5.13 Effective collaboration between Aged Health Care and Specialist Mental Health Services for Older People.</td>
<td>5.13.1 (see next section)</td>
</tr>
<tr>
<td>5.14 Access to Transitional Aged Care Program for people with dementia.</td>
<td>5.14.1 Identify and promote the benefits of the NSW Transitional Aged Care program for people with dementia.</td>
</tr>
<tr>
<td>5.15 Access to sub-acute and post-acute care services for people with dementia.</td>
<td>5.15.1 Increase access to specialist support or shared care models for sub-acute and post-acute services.</td>
</tr>
</tbody>
</table>
### 6. Residential Care

<table>
<thead>
<tr>
<th>Key requirements</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.1 Local facilities that are able to provide accessible quality care for people with dementia with a range of diverse needs.</td>
<td>6.1.1 Encourage and support facilities to develop high quality care such as outlined in Quality Care Standards developed by AA.</td>
</tr>
<tr>
<td>6.2 Safe, dementia-friendly environment that supports person-centred care, provides sufficient privacy and spaces for socialisation and provides a range of appropriate activities.</td>
<td>6.2.1 Promote and implement evidence based dementia design.</td>
</tr>
<tr>
<td>6.3 Carer support during transition and while a person is in residential care.</td>
<td>6.3.1 Provide support to carers during transition and while person is in residential care.</td>
</tr>
</tbody>
</table>
| 6.4 Access to primary health care with dementia care knowledge – GPs, practice nurses, NPs, CNCs and CNSs trained in dementia care. | 6.4.1 Provide incentives for GPs/practice nurses to develop dementia care knowledge.  
6.4.2 Increase residential aged care access to NPs, CNCs and CNSs trained in dementia care. |
| 6.5 Strong partnerships between RACFs, GPs and aged health care service to avoid unnecessary admissions. | 6.5.1 Develop acute residential care clinical support services, including after hours, to assist GPs and RACF staff to provide care within the person’s usual environment and avoid unnecessary admissions. |
| 6.6 Well trained and supported staff. | 6.6.1 Implement strategies to attract, retain and support staff in RACFs.  
6.6.2 Provide cultural competency training to residential staff. |

### 7. Behavioural and Psychological Symptoms of Dementia

<table>
<thead>
<tr>
<th>Key requirements</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.1 Provision of culturally appropriate education on person-centred care and management of BPSD to carers, GPs, community care, community health, hospital and residential care staff and volunteers.</td>
<td>7.1.1 Expand positions that provide advice and education on person-centred care and management of BPSD in community, acute and residential care.</td>
</tr>
</tbody>
</table>
| 7.2 Provision of services that provide support, information and specialist advice to workers where a person is living. | 7.2/7.3/7.4.1 Continue to implement the SMHSOP Service Plan, including:  
7.2/7.3/7.4.1a Expand community based BASIS and DBMAS programs for people with moderate and severe BPSD and carers.  
7.2/7.3/7.4.1b Develop and expand sub-acute/non-acute transitional assessment and treatment units for severe BPSD.  
7.2/7.3/7.4.1c Establish specialist intensive care units for very severe BPSD. |
| 7.3 Access to sub-acute/non-acute transitional assessment and treatment units for people with dementia and severe BPSD eg T-BASIS. | |
| 7.4 Access to specialised intensive care units for people with very severe BPSD. | |
| 7.5 Access to SMHSOP with strong partnerships with aged health care services. | 7.5.1 Develop clearly defined roles for SMHSOP and aged health services for all community and hospital networks with mechanisms for review and resolution of any role disputes at clinical or service level. Develop effective governance systems to facilitate the above. |
| 7.6 Access to a local residential care facility that can cater for people with severe BPSD. | 7.6.1 Further develop specialist programs/units within RACFs for people with severe behavioural disturbance. |
### 8. Palliative Care

<table>
<thead>
<tr>
<th>Key requirements</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>8.1</strong> A palliative care approach adopted for people with advanced dementia and access to specialist palliative care when required.</td>
<td>8.1.1 Continue to implement the Guidelines for a Palliative Approach in Residential Aged Care, including culturally sensitive palliative care training for residential care staff.</td>
</tr>
<tr>
<td></td>
<td>8.1.2 Support the implementation of good practice examples that result from the Dementia Palliative Care Projects funded under Round five of the National Palliative Care Program.</td>
</tr>
<tr>
<td></td>
<td>8.1.3 Promote evidence based resources developed under Dementia Palliative Care Projects.</td>
</tr>
<tr>
<td></td>
<td>8.1.4 Identify and support the use of best practice models for pain assessment and management for persons with dementia across all settings.</td>
</tr>
<tr>
<td></td>
<td>8.1.5 Clarify role of AHSs specialist palliative services in dementia in acute, residential and community care.</td>
</tr>
<tr>
<td><strong>8.2</strong> Plan of care discussed with person with dementia and/or Person Responsible, their GP and relevant care staff documented and implemented.</td>
<td>8.2.1 Implement initiatives to increase community awareness of advance care planning.</td>
</tr>
<tr>
<td></td>
<td>8.2.2 Discuss advance care planning and document on admission to residential care.</td>
</tr>
<tr>
<td><strong>8.3</strong> Family case conferences and information on advanced stage of dementia provided.</td>
<td>8.3.1 Conduct family case conferences and provide culturally sensitive information on advanced dementia.</td>
</tr>
<tr>
<td><strong>8.4</strong> Staff training in palliative care and advance care planning.</td>
<td>8.4.1 Provide training for relevant health and community care staff on advance care planning and their responsibilities, advanced dementia and end of life care, including the use of non-verbal observational validated pain assessment tools.</td>
</tr>
<tr>
<td><strong>8.5</strong> Counselling and bereavement support for carers.</td>
<td>8.5.1 Increase access to counselling and bereavement support for carers when required.</td>
</tr>
</tbody>
</table>
Factors contributing to chronic disease in Aboriginal people

Figure 5. Factors contributing to chronic disease in Aboriginal people.27

APPENDIX 2

Factors contributing to chronic disease in Aboriginal people

HISTORICAL
- Dispossession
- Loss of land
- Loss of culture
- Forced family separation

ECONOMIC
- High unemployment rates
- Poverty

PSYCHO-SOCIAL/ CULTURAL
- Physical, emotional abuse
- Trans-generational trauma
- Racism
- Low self esteem
- Depression & related disorders
- Stress
- Educational disadvantage
- Disempowerment

HEALTH CARE SYSTEM ACCESS
- Affordability
- Availability
- Appropriateness/responsiveness
- Utilisation

RISK BEHAVIOURS
- Physical inactivity
- Poor diet and nutrition
- Smoking
- Excessive alcohol use
- Substance abuse

NON-MODIFIABLE RISK BEHAVIOURS
- Age
- Gender
- Genetics

BIOMEDICAL RISK FACTORS
- Body mass
- High blood lipids
- High blood pressure
- Impaired glucose metabolism
- Low birth weight

ENVIRONMENTAL
- Inadequate housing
- Unsafe environment
- Physical isolation
- Lack of transport
- Poor food supply
- Lack of recreational facilities

CHRONIC CONDITIONS
Cardiovascular diseases, kidney disease, diabetes, chronic obstructive pulmonary disease, asthma and cancer

## Programs/Services for people with dementia and their carers

<table>
<thead>
<tr>
<th>Service focus</th>
<th>Commonwealth funded</th>
<th>Joint funded</th>
<th>NSW funded</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>General</td>
<td>Dementia specific</td>
<td>General</td>
</tr>
<tr>
<td>Dementia awareness (Community awareness and risk reduction)</td>
<td>GP 45+ assessment</td>
<td>Dementia Community Support Grants targeting promotion &amp; awareness raising</td>
<td>Dementia Advisory Services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Alzheimer’s Australia, Mind Your Mind</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dementia Community Support Grants targeting risk reduction</td>
<td></td>
</tr>
<tr>
<td>Assessment, diagnosis and ongoing management</td>
<td>GPs, Practice nurses</td>
<td>Positions in rural ACATs under the Dementia Support for Assessment Program</td>
<td>ACATs (Functional assessment – HACC services)</td>
</tr>
<tr>
<td></td>
<td>Private specialists</td>
<td>Pharmaceutical Benefits Scheme (Cholinesterase inhibitors)</td>
<td></td>
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<tr>
<td></td>
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</tr>
<tr>
<td>Information counselling and carer education</td>
<td>Commonwealth Respite and Carelink Services (CRCC) 1800 052 222</td>
<td>National Dementia Support Program - Dementia Helpline 1800 100 500 - counselling service - Carer education - LWML Program - Cross cultural network</td>
<td>Single point of access pilot ACATs</td>
</tr>
<tr>
<td></td>
<td>GPs, Practice nurses</td>
<td></td>
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</tr>
<tr>
<td>Community case management</td>
<td>GPs, Practice nurses</td>
<td>EACH - Dementia</td>
<td>General HACC funded Community Options</td>
</tr>
<tr>
<td></td>
<td></td>
<td>ACATs</td>
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<tr>
<td></td>
<td></td>
<td>Transitional Aged Care Program (TACPs)</td>
<td></td>
</tr>
</tbody>
</table>

APPENDIX 3

The NSW Dementia Services Framework 2010 – 2015

PAGE 80
<table>
<thead>
<tr>
<th>Service focus</th>
<th>Commonwealth funded</th>
<th>Joint funded</th>
<th>NSW funded</th>
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</thead>
<tbody>
<tr>
<td>Community support services</td>
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<tr>
<td></td>
<td>General</td>
<td>Dementia specific</td>
<td>General</td>
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<tr>
<td>Community Aged Care Packages (CACPs)</td>
<td>EACH – Dementia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extended Aged Care in the Home (EACH)</td>
<td>Dementia Community Support Grants targeting local support for families and/or carers</td>
<td></td>
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<tr>
<td>Veterans Home Care</td>
<td>Dementia specific</td>
<td></td>
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<tr>
<td>National Respite for Carers Program (NRCP)</td>
<td>Respite services</td>
<td></td>
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<tr>
<td>Hospital care</td>
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<td></td>
<td>Acute to Age Related Care Services (AARCS)</td>
<td></td>
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<tr>
<td></td>
<td>Aged Care Services in Emergency Teams (ASETs) funded under COAG Long stay older patients initiative</td>
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<tr>
<td>Residential care</td>
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<td></td>
<td>RACFs</td>
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<td>Aged health services</td>
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<tr>
<td></td>
<td>GPs Aged Care Access Initiative (ACAI) including Allied Health Services component</td>
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<td></td>
<td>Aged Care Funding Instrument (ACFI)- behaviour supplement</td>
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<td></td>
<td>DBMAS</td>
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<tr>
<td>Behavioural support</td>
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<td></td>
<td>GPs</td>
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<td></td>
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<tr>
<td></td>
<td>Dementia Behaviour Management and Advisory Services (DBMAS)</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Any new services to be funded National Partnership Agreement on Subacute Care for psychogeriatrics</td>
<td></td>
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<tr>
<td>Palliative care</td>
<td></td>
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<tr>
<td></td>
<td>Services to be funded under National Partnership Agreement on Subacute Care – palliative care</td>
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<td></td>
<td>Dementia / palliative care grants</td>
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<td></td>
<td>GPs</td>
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</tbody>
</table>
Dementia Advisory Services (DASs) fulfil a critical role in the dementia service pathway, providing information, counselling, carer education and support to people with dementia, their carers and families at any stage from initial concerns to support to bereaved carers. They also provide information and education to the general public about dementia and where to get help.

Most DASs are a single position that services a defined geographic area (see maps for DAS locations across NSW and in the Sydney metropolitan region). DAS are ADHC funded under the HACC Program, the Ageing Grants Program of the Office of Ageing or both. Some positions are funded on a part-time basis. DAS positions have varied auspices, including NSW Health aged health services, AANSW and other NGOs which increase the variability of services provided. HACC funded DAS have a client load, meet outputs and carry out Minimum Data Set reporting whereas Ageing Grants Program funded DASs have a more community development and capacity building emphasis.

Importantly, the role of the DAS has grown in response to the needs of people with dementia, their carers and families to include many service functions in the absence of other dementia-specific services being available. This includes:

- Providing information about dementia;
- Providing assistance with referral to other services;
- Facilitating access to carer education and resources;
- Providing access to short term counselling;
- Promoting community awareness of dementia, including the benefits of early diagnosis and support services available;
- Working with other services to improve coordination and the strengthening of links between dementia-specific services and other locally relevant services;
- Providing support to local networks of carers seeking peer support; and
- Promoting access to dementia training and educational opportunities.

Continuation of the DAS in the context of the Framework needs to acknowledge that dual functions have emerged for these positions since their inception. This includes:

1. Undertaking service coordination responsibilities for a geographic area such as planning and dementia service networking activities, promoting public dementia awareness and providing information services, convening carer support groups and educational activities, conducting training for other service providers and community groups, and development of interagency protocols and pathways to support people to navigate local dementia service networks.

2. Providing direct care services and case coordination for people with dementia, their carers and families consistent with the "key worker" function. This will often involve maintaining continuing contact with a person and their carer over long periods of time, providing intensive support during periods of crisis or where possible referring on to case management services such as Community Options.

The Framework identifies the need for clarification and delineation between these two separate DAS functions so that DAS responsibilities for service coordination, planning and development can continue at a local level among multiple community stakeholders to improve programs and services. However, this should not be at the cost of reducing the provision of case coordination and direct care services of people with dementia, their carers and families. The reverse also applies. Both functions are important for quality dementia care.
Note: Maps of Dementia Advisory Service coverage within NSW by LGA/ADHC region have been developed by AANSW from up-to-date DAS contact list and provides indication of DAS distribution.
Background:

One of the most significant challenges arising from NSW’s ageing population is the predicted increase in the numbers of people in the future who will be living with dementia.

The policy response in NSW has most recently been progressed under the NSW Dementia Action Plan 2007-2009, with responsibilities for action shared between the NSW Department of Health and Ageing, Disability and Home Care (ADHC).

The development and implementation of this plan has been:

- consistent with the principles of the National Framework for Action on Dementia 2006-2010, and
- responsive to and integrated with other key NSW government policy statements including the NSW State Plan, NSW State Health Plan, and Towards 2030: planning for our changing population.

With the conclusion of the NSW Dementia Action Plan 2007-2009 a successive strategic planning process is required to assist in developing polices and planning services to address the expected increase in people living with dementia in NSW and the needs of their families and carers. This planning process will be led by this Steering Committee.

Purpose:

The purpose of the Steering Committee is to oversee the development of a NSW Dementia Services Framework that complies with appropriate planning principles and is consistent with the state and national policy environment on dementia. The Framework will provide recommendations to the NSW Department of Health and Ageing, Disability and Home Care on future directions for dementia policies and services to meet the needs of people in NSW.

The Steering Committee is the governance body for the development of the NSW Dementia Services Framework to ensure that it:

- Provides state-wide strategic direction to dementia policies and services development and provision within the responsibilities of the NSW Government.
- Addresses the needs of the NSW community now and into the future.
- Is consistent with National, NSW Health and ADHC strategic directions, plans, priorities and policies.
- Reflects current evidence in effective interventions for improving the quality of life for people living with dementia, their carers and families.
- Is developed through consultation and communication with key stakeholders including consumers, community members, NSW Health and ADHC staff, service providers and other government and non-government agencies.
- Takes account of the needs of all people living with dementia, their carers and families regardless of age, gender, cultural background or location.
- Is developed with appropriate processes and in a timely manner.
An **Expert Advisory Group** will be established to provide expert input into the identification of service models and the current demands and challenges in the service system. The Expert Advisory Group will report to the Steering Committee. The Steering Committee will be responsible for:

- Endorsing the scope, parameters and timeframes of the work of the Expert Advisory Group.
- Review and endorsement of reports provided by the Expert Advisory Group to the Steering Committee.

In undertaking their work, the Steering Committee and Expert Advisory Group will liaise closely with the Commonwealth on its National Dementia Pathways Project.

### Business Rules:

**Chair**

- The delegated chair will be the Deputy Director-General, Strategic Development Division, NSW Department of Health

**Members**

- Members are appointed to the Steering Committee from October 2009 until 30 June 2010, unless otherwise agreed.
- Members’ contributions will be through review of meeting papers, attendance at Steering Committee meetings and responding to matters raised out of session by the Chair.
- Members of the Steering Committee will respond to requests from the Chair in a timely manner, treat material as private and confidential, and attend meetings as scheduled.
- The Steering Committee will meet approximately every three months for up to 2-3 hours on each occasion. The meeting length will be determined by the agenda items.
- The agenda will be confirmed at least 1 week prior to each meeting.
- Extraordinary meetings may be scheduled at the request of the Chair, if required.
- Members will attend meetings in person. If this is not possible, members should alert the secretariat about an appropriate delegate in advance of the meeting. Where necessary, teleconference facilities can be arranged by notifying the secretariat at least 1 week in advance of the meeting.

### Secretariat

- The Dementia Policy Team within the South Eastern Sydney Illawarra Area Health Service will provide secretariat support. The agenda, meeting papers and minutes will be provided to members in a timely manner.
- Meetings will be held at the Department of Health.

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<table>
<thead>
<tr>
<th>Name/ Title</th>
<th>Title</th>
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<tbody>
<tr>
<td>Chair: Richard Matthews</td>
<td>DDG, Strategic Development, DoH</td>
</tr>
<tr>
<td>Chris Leach</td>
<td>Executive Director OFA ADHC Northern Region</td>
</tr>
<tr>
<td>John Watkins</td>
<td>Chief Executive, Alzheimer’s Australia NSW</td>
</tr>
<tr>
<td>Cathrine Lynch</td>
<td>Director, Primary Health &amp; Community Partnerships Branch Strategic Development Division, DOH</td>
</tr>
<tr>
<td>Sigrid Patterson</td>
<td>Director, OFA, ADHC</td>
</tr>
<tr>
<td>Henry Brodaty</td>
<td>Director, Aged Care Psychiatry, Prince of Wales Hospital, SESIAHS</td>
</tr>
<tr>
<td>Elizabeth Koff</td>
<td>Director, Clinical Operations, SESIAHS</td>
</tr>
<tr>
<td>David Miles</td>
<td>Planning Manager, North Sydney Central Coast Area Health Service</td>
</tr>
<tr>
<td>Steven Gal</td>
<td>ADHC Regional Manager of Planning, ADHC</td>
</tr>
<tr>
<td>Secretariat: Anne Cumming</td>
<td>Principal Policy Officer, Dementia Policy Team, SESIAHS</td>
</tr>
<tr>
<td>Secretariat: Troy Speirs</td>
<td>Policy Officer, Dementia Policy Team, SESIAHS</td>
</tr>
</tbody>
</table>
Background:

One of the most significant challenges arising from NSW’s ageing population is the predicted increase in the numbers of people in the future who will be living with dementia.

The policy response in NSW has most recently been progressed under the *NSW Dementia Action Plan 2007-2009*, with responsibilities for action shared between the Department of Health and Ageing, Disability and Home Care, Department of Human Services.

The development and implementation of this plan has been:

- consistent with the principles of the *National Framework for Action on Dementia 2006-2010*, and
- responsive to and integrated with other key NSW government policy statements including the *NSW State Plan, NSW State Health Plan*, and *Towards 2030: planning for our changing population*.

With the conclusion of the *NSW Dementia Action Plan 2007-2009* a successive strategic planning process is required to assist in developing polices and planning services to address the expected increase in people living with dementia in NSW and the needs of their families and carers.

NSW Department of Health and Ageing, Disability and Home, Department of Human Services have committed to the development of a joint NSW Dementia Services Framework.

Governance:

A Steering Committee with representation from NSW Health, ADHC and Alzheimer’s Australia NSW has been formed to oversee the development of a NSW Dementia Services Framework to ensure that complies with appropriate planning principles and is consistent with the state and national policy environment on dementia. The Framework will provide recommendations to the NSW Department of Health and Department of Ageing, Disability and Home Care on future directions for dementia policies and services to meet the needs of people in NSW. The NSW Dementia Expert Advisory Group will report to the Steering Committee.

Purpose:

The Framework will identify service models along the pathway from risk reduction to palliative care. The purpose of the Expert Advisory Group is to:

- Provide expert clinical and research advice to assist in the development of a NSW Dementia Services Framework by July 2010.
- Identify evidence based service models that work or could work well within the current demands and challenges facing the health, aged and community care system in NSW.
- Assist in the consultation process for the development of NSW Dementia Services Framework through identifying and linking to other key contacts and participating in consultation workshops.
## Membership of the Dementia Expert Advisory Group

<table>
<thead>
<tr>
<th>Name/ Title</th>
<th>Organisation</th>
<th>Representation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chair: Henry Brodaty Director</td>
<td>Aged Care Psychiatry, Prince of Wales Hospital and Dementia Collaborative Research Centre - Assessment and Better Care</td>
<td>Aged care psychiatry Dementia research Dementia Policy Team</td>
</tr>
<tr>
<td>Joanne Young A/Associate Director</td>
<td>Primary Health &amp; Community Partnerships Branch, NSW Health</td>
<td>NSW Department of Health</td>
</tr>
<tr>
<td>Clare Gardiner, Area Performance Manager and Project Director</td>
<td>Health Service Performance Improvement Branch, NSW Health</td>
<td>NSW Department of Health</td>
</tr>
<tr>
<td>Lisa Langley, Manager, Policy and Advocacy</td>
<td>Alzheimer’s Australia NSW</td>
<td>Consumer and carer</td>
</tr>
<tr>
<td>Anne Moehead, Nurse Practitioner, Psychogeriatrics,</td>
<td>NCAHS</td>
<td>Acute care and rural</td>
</tr>
<tr>
<td>John Ward Geriatrician</td>
<td>HNEAHS, Greater Metropolitan Clinical Taskforce (GMCT) Aged Care Group representative</td>
<td>Aged care - acute and community</td>
</tr>
<tr>
<td>Bill Doherty</td>
<td>Goulburn Aged Care Assessment Team</td>
<td>Assessment</td>
</tr>
<tr>
<td>Rod McKay Clinical Advisor</td>
<td>Older Peoples Mental Health</td>
<td>Behavioural and psychological symptoms of dementia</td>
</tr>
<tr>
<td>Dimity Pond Chair</td>
<td>GP Dementia Working Group Professor, Discipline of General Practice University of Newcastle</td>
<td>Primary care</td>
</tr>
<tr>
<td>Janine Lundie, Policy Manager</td>
<td>Aged and Community Services Association of NSW &amp; ACT Inc (ACS)</td>
<td>Residential care</td>
</tr>
<tr>
<td>Kay Richards, Manager, Member Services</td>
<td>Aged Care Association Australia – NSW (ACAA- NSW)</td>
<td>Residential care</td>
</tr>
<tr>
<td>Libby Palmer</td>
<td>Northern Beaches Dementia Advisor Community Care (Northern Beaches)</td>
<td>Community care</td>
</tr>
<tr>
<td>Rosemary Fraser SSWAHS HACC Coordinator</td>
<td>Representative from Home and Community Care Program (HACC)</td>
<td>Community care</td>
</tr>
<tr>
<td>Colleen Cartwright</td>
<td>Aged Services Learning &amp; Research Centre Southern Cross University</td>
<td>End of life decision making/advance care planning</td>
</tr>
<tr>
<td>Peter Cleasby, Chair</td>
<td>NSW Palliative Care Advisory Group President Palliative Care NSW</td>
<td>Palliative care</td>
</tr>
<tr>
<td>Lee-Fay Low</td>
<td>Dementia Collaborative Research Centre-Assessment and Better Care</td>
<td>CALD</td>
</tr>
<tr>
<td>Adrienne Withall</td>
<td>Aged Care Psychiatry, POWH/Dementia Collaborative Research Centre - Assessment and Better Care</td>
<td>Younger Onset</td>
</tr>
<tr>
<td>Tony Broe</td>
<td>Neuroscience Research Australia Professor Geriatric Medicine, UNSW</td>
<td>Aboriginal dementia research</td>
</tr>
<tr>
<td>Gail Daylight</td>
<td>Aboriginal Health Manager, SESIAHS</td>
<td>Aboriginal representative</td>
</tr>
<tr>
<td>Glenn Williams</td>
<td>NSW Aboriginal Health and Medical Research Council</td>
<td>Aboriginal representative</td>
</tr>
<tr>
<td>Anne Cumming, Principal Policy Officer</td>
<td>NSW Dementia Policy Team, SESIAHS</td>
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Business Rules:

Chair
- The delegated chair will be Henry Brodaty, Director, Aged Care Psychiatry, Prince of Wales Hospital and the Primary Dementia Collaborative Research Centre.

Members
- Members are appointed to the Advisory Group from November 2009 until 30 June 2010, unless otherwise agreed.
- Members’ contributions will be through review of meeting papers, attendance at meetings, linkage to other experts and responding to matters raised out of session by the Chair. Members will also be invited to attend workshops, to be determined.
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- Meetings will be held at the AGSM Building, University of New South Wales.
Consultation for the development of the NSW Dementia Services Framework

Purpose

The purpose of the consultation for the Framework was to assist in identifying key evidence-based or good practice service models along the pathway, identifying current challenges and barriers and outlining key components required for successful implementation.

Stakeholders

The main methods of consultation:

- Advisory Group participation
- Workshops – March/May 2010
- Invitation to comment on draft documents through written requests, e-newsletters and websites.

Scope

Consultations have focused on what service models along the pathway are working well, what needs improvement and how they can be improved.

Workshops

1. Joint workshop with KPMG for National Dementia Pathways Project
   - Statewide workshop
   - Three case studies – Fairfield (CALD), Hunter and Wagga
2. Nine service provider dementia networks workshops – March – May 2010
3. AAG Conference consultation workshop – 16 April 2010
   – Ballina
4. Aboriginal specific workshop – 25 May 2010
5. Remote region videoconference workshop – 25 May 2010
6. Consultation with consumers and carers through eight AANSW Regional Consumer Committees
7. Consultation with managers from AANSW
8. Consultation with NSW General Practice Council
9. Consultation with NSW Council of Social Services (NCOSS) Gathering

Consultation workshops for the Framework have involved the participation of near 350 service providers and 50 consumers/carers from across NSW for which a presentation was provided on development of the Framework and through which information was collated. Consultations were conducted in inner and outer metropolitan, regional and rural communities across NSW, some of which targeted the needs of Aboriginal, CALD and remote community service provision for dementia care.