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Future Directions

for Dementia Care and Support
in NSW 2001-2006



NSW HEALTH
Working as a Team



Future Directions for Dementia Care and Support in NSW 2001–2006

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Department of Ageing, Disability and Home Care

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Foreword

Our population is ageing and ageing brings an increased risk of dementia. The number of people with dementia will increase rapidly. It is crucial that we are able to respond in a planned, sensitive and equitable way.

Future Directions for Dementia Care and Support in NSW 2001-2006 reaffirms the NSW Government's commitment to people living with dementia and their families, carers, friends and neighbours. It provides direction for our energies and efforts over the next five years. It reminds us that these efforts must be in partnership and that it is only through collective initiatives that we can improve services for people with dementia.

Future Directions for Dementia Care and Support in NSW 2001-2006 builds on the success and the lessons from the previous *NSW Action Plan on Dementia 1996-2001*. It continues a comprehensive approach to dementia through eight key focus areas that cover a range of issues from diagnosis to palliative care.

The NSW Government has demonstrated its commitment through the allocation, in the May 2001 State budget, of \$11.043 million over 4 years to implement *Future Directions for Dementia Care and Support in NSW 2001-2006*. This is in addition to existing funding for dementia support provided by a range of health and community-based service providers.

Initial funding of \$5.8 million has been allocated to demonstration and recurrent projects for 2001- 2003. To incorporate emerging issues, demonstration projects will be reviewed in 2 years as part of a general review of the *Future Directions* strategies. The review will inform recurrent funding priorities for 2003 and beyond. The NSW Dementia Reference Group, comprising all key stakeholders, will inform these priorities.

Both NSW Health and the Department of Ageing, Disability and Home Care are committed to this initiative, and to working in partnerships with others to improve services for people with dementia and their families, friends and carers.



Craig Knowles MP
Minister for Health



Carmel Tebbutt MLC
Minister for Community Services
Minister for Ageing
Minister for Juvenile Justice
Minister Assisting the Premier on Youth

Future Directions for Dementia Care and Support in NSW

2001-2006...provides direction for our energies and efforts over the next five years. It reminds us that these efforts must be in partnership and that it is only through collective initiatives that we can improve services for people with dementia.

Executive Summary

In the 2001 budget, the NSW Government reaffirmed its commitment to dementia care with its announcement of a further \$11.043 million over 4 years for a second strategy. *Future Directions for Dementia Care and Support in NSW 2001–2006* was subsequently developed by the Department of Ageing, Disability and Home Care (DADHC) and NSW Health in consultation with a wide range of stakeholders.

Future Directions for Dementia Care and Support in NSW 2001–2006 works towards informing the public of the issue of dementia, promoting good primary care and providing opportunities for people with dementia to plan for their future and to participate fully in society. The document also works towards providing recognition and support for carers, timely and equitable access to appropriate community support, targeted training for staff, access to expertise and resources for the prevention and management of behavioural complications, responsive medical treatment that supports recovery and rehabilitation, timely access to high level care, an integrated local planning approach and support for families in decision making in the final stages of dementia.

Future Directions for Dementia Care and Support in NSW 2001–2006 gives recognition to prevention, where feasible, and the benefits of early diagnosis in the context of developments in drug therapies that can slow down the symptoms of Alzheimer's Disease and increase a person's functioning. Recognition is also given to dementia in parts of the community that have specific prevention, assessment, treatment and care issues.

Groups that are recognised as having particular needs include younger age groups, Aboriginal people, people from linguistically and culturally diverse backgrounds, those living in rural areas and people with an intellectual disability. Issues regarding access to a full range of dementia services by these groups are targets for intervention in *Future Directions for Dementia Care and Support in NSW 2001–2006*.

It is also important to recognise that there is a range of Government Departments at both the Commonwealth and State level involved in providing dementia-related services, together with public and non-government organisations. For this reason, the development of effective partnerships, service coordination and recognition that dementia is an integral part of business across these organisations, are key elements for improved service delivery for people with dementia and their carers.

Future Directions for Dementia Care and Support in NSW 2001–2006 highlights eight focus areas for intervention: policy and planning; supportive and inclusive communities; diagnosis, assessment and management; education and training; community support services; acute care; accommodation options and protection of rights and interests.

Future Directions for Dementia Care and Support in NSW

2001-2006 works towards informing the public of the issue of dementia, promoting good primary care and providing opportunities for people with dementia to plan for their future and to participate fully in society.

Whilst *Future Directions for Dementia Care and Support in NSW 2001–2006* is a five year strategy that provides the policy direction, guiding principles and the aims of key focus areas, NSW Health and DADHC have developed specific strategies for the next two years 2001–2003. The implementation of these strategies will be led by the Office for Ageing of DADHC and the Primary Health and Community Care Branch of the NSW Health Department. Further strategies will be developed after a review in two years. This will ensure that implementation is flexible, responsive and appropriate within the context of a changing environment.

For the 2 year period 2001–2003, funding of \$5.8 million has been allocated to the focus areas to support demonstration and recurrent projects. Demonstration projects will be reviewed in 2 years to inform recurrent funding priorities for 2003 and beyond. The NSW Dementia Reference Group, comprising all key stakeholders, will inform these priorities. Appendix A provides a list of strategies and indicative funding available for each focus area for 2001–2003. Members of the Reference Group are listed at Appendix B. Following is a summary of the eight focus areas.

Focus Area 1: Policy and Planning

As responsibility for dementia care crosses a number of Commonwealth and NSW Departments, the clarification of roles and responsibilities of these departments would assist dementia care, including the areas of community based and residential psychogeriatric services.

There is also a clear need for timely and meaningful data from all service sectors including acute inpatient, community-based, residential care, accommodation and community support to accurately reflect the impact of dementia on the service system. Improved and integrated data collections will support improved policy development and service planning. Important steps towards improved policy and planning include mapping current services and funding sources, reviewing existing data sets, identifying key elements required for effective dementia care and developing recommended service profiles.

Under the *NSW Action Plan on Dementia 1996–2001* Area Health Services across NSW were funded to develop local dementia service plans. This was an important step in creating a planning environment for dementia service delivery in health services. Because a range of health and non-health, public and non-government organisations provide services to people with dementia, *Future Directions for Dementia Care and Support in NSW 2001–2006* will further strengthen local planning by providing support and funding to local dementia planning and service development strategies. These will include enhancing local joint planning initiatives, clarifying and improving referral pathways, identifying opportunities for resource sharing, developing local projects, and sharing expertise.

Focus Area 2: Supportive and Inclusive Communities

It is important that community awareness strategies promote the advantages of early action, convey a positive image of people living with dementia and provide information that promotes appropriate access to services and support. Awareness of dementia, however, varies considerably across the population.

NSW Health and DADHC will implement strategies to enhance community awareness, address the needs of Aboriginal communities, improve awareness of dementia among diverse cultures and promote supportive and inclusive community environments.

Focus Area 3: Diagnosis, Assessment and Management

Key issues include acknowledging and addressing the impact of the caring role on carers, the need to specifically target people who live alone for assessment in early stages of dementia, the growing number of people with intellectual disability who are ageing and the management of challenging behaviours in a range of care settings.

This Focus Area acknowledges the crucial role of a range of services and professionals involved in the assessment and support of people with dementia and the need for partnerships and linkages between them. In particular, where behavioural problems exist it is important that flexible models of care are developed and any specialised interventions are enhanced through partnerships between psychogeriatric, primary care and aged care services.

Focus Area 4: Education and Training

The expansion of workforce education and training is crucial to the provision of quality services in dementia prevention, assessment, management and care. Challenges for education and training are the variety of settings in which dementia services are provided and the high staff turnovers and recruitment difficulties that are commonly experienced by these services. In providing training it is important that the knowledge, skills and qualifications of staff are appropriately matched with care needs in a range of settings. While the Commonwealth has developed a number of training initiatives such as the Community Services Training Package, services are experiencing difficulties in providing education and training for the nursing profession, in particular within the context of the shortage of nurses.

In this context, education and training in *Future Directions for Dementia Care and Support in NSW 2001–2006* focuses on strategies that will increase carer access to education; support GP education that improves diagnosis, management and referral processes; and provide improved access to dementia training for critical sections of the NSW workforce.

Focus Area 5: Community Support Services

The informal care provided in the community setting is complemented by services such as those available through the Home and Community Care Program (HACC), the Veterans' Home Care Program (VHC) and the Commonwealth's Community Aged Care Packages (CACPs). With increasing demands on such services by people with dementia, the focus will be on improving access to information, education, employment assistance, counselling and peer support for people in the early stages of dementia or with an early onset; expanding the availability of a range of community support services; supporting carers; and improving access to expertise on the management of challenging behaviour for community support services and family carers.

Focus Area 6: Acute Care

People with dementia experience the full range of acute illnesses that require hospitalisation. As hospitals are focused on providing efficient and effective treatment for acute illness, the specific needs of people with dementia may not be adequately addressed in the acute setting. Management difficulties can arise in the initial response in Emergency Departments, in the individual care environment, in the detection of delirium, in gaining compliance with treatment and in discharge planning. *Future Directions for Dementia Care and Support in NSW 2001–2006* includes a focus on improving dementia diagnosis and management in public hospitals, making hospital settings more appropriate, developing alternatives to hospital admission and ensuring that the needs of people with dementia and their carers are incorporated into discharge planning.

Focus Area 7: Accommodation Options

The NSW Government is committed to supporting and improving the range of accommodation options for people with dementia. *Future Directions for Dementia Care and Support in NSW 2001–2006* includes strategies aimed at maintaining the independence and safety of people with dementia in the home setting; developing appropriate accommodation options for people with challenging behaviour, younger people with dementia and people with an intellectual disability and dementia; increasing the capacity of mainstream aged care facilities to respond to people with challenging behaviours; improving access to appropriate residential care in rural areas, and improving access to appropriate care for people from culturally and linguistically diverse backgrounds.

Focus Area 8: Protection of Rights and Interests

Most people with dementia are cared for by family members who take responsibility for decision making on an informal basis. With early diagnosis, planning for future decision making is one of the most important actions that can be taken to reduce anxiety, confusion, untimely loss of independence, family conflict and conflict with service providers (Department of Human Services 1997).

Future Directions for Dementia Care and Support in NSW 2001–2006 promotes improved decision making and protection of the rights and interests of people with dementia. The strategies are aimed at increasing access for people in early stages of dementia to information and opportunities for planning ahead; introducing mechanisms that will further protect the rights and interests of people with dementia; providing support for families involved in decisions on clinical management; and increasing access to palliative care for people with dementia in their final stages of life.

In conclusion, *Future Directions for Dementia Care and Support in NSW 2001–2006* provides NSW with an integrated and comprehensive strategy to respond to the complex needs of people with dementia, their carers and service providers. The development of effective partnerships between people with dementia and their advocates, carers, a range of service providers, Government Departments, non-government organisations and the tertiary education sector are integral to the success of this initiative.

What are we working towards in NSW?

- An informed public that can recognise possible signs of dementia, understands the benefits of early intervention and knows where to seek help.
- Good primary health care where Nurses, General Practitioners, Aged Care Assessment Teams, other health professionals and service providers in partnership, encourage preventative measures, investigate a person's and/or carer's concerns, refer for appropriate diagnostic assessment, provide links to information and support services and participate in ongoing management to improve health and social outcomes.
- Opportunities for people in the early stage of dementia and their future carers to plan ahead, to receive counselling and participate in support and education programs.
- An inclusive society where people with dementia are encouraged to live as normal a life as possible, participate in society and where they experience as little restriction as possible¹ and their families and carers feel supported.
- Recognition of the vital and changing role of carers in maintaining the person's quality of life, through carer education, enhancing carer supports and opportunities for effective consultation.
- Support for carers so that their caring role is not detrimental to their health.
- Timely access to appropriate services for people with dementia, their families and carers that responds to their diversity of needs.
- Responsive, trained staff in all settings (community, acute care and residential aged care).
- A caring environment that supports independence and respects a person's dignity whether they are at home, in hospital or in residential care.
- Timely and available expertise and resources to prevent, assess and manage behavioural complications arising from dementia in a range of settings.
- Treatment in an acute care environment that is responsive to dementia and supports recovery and rehabilitation.
- An integrated planning approach at local, regional and statewide levels where agencies work together to address the needs of their community in relation to dementia.
- Support for families in making decisions regarding medical intervention, including managing advanced care directives and arranging access to palliative care in the final stages.

¹ Adherence to the *Guardianship Act* principles.

Section 1: Introduction

The *NSW Action Plan on Dementia 1996–2001* (Ageing and Disability Department 1996b) achieved a range of important initiatives, including practical information for carers, Area Health Service dementia planning and dementia awareness programs for the general community and for professionals.

The Department of Ageing, Disability and Home Care (DADHC) and NSW Health have now developed a second strategy to cover the next 5-year period: *Future Directions for Dementia Care and Support in NSW 2001–2006*. This document is designed to promote a coordinated, planned response to the expected rapid rise in the number of people living with dementia in NSW.

There were considerable achievements from the first plan, *NSW Action Plan on Dementia 1996–2001*. The strategies, achievements and momentum from the *NSW Action Plan on Dementia 1996–2001* were used to develop *Future Directions for Dementia Care and Support in NSW 2001–2006* with the aim of achieving further improvement in services for people with dementia and their carers.

This document includes specific strategies for the 2001–2003 period (Appendix A). Further strategies will be developed after a 2-year review. This will ensure strategies remain appropriate within the context of a changing environment.

Future Directions for Dementia Care and Support in NSW 2001–2006 provides the policy context and priorities for the future direction of dementia supports and services in NSW.

It does not describe funding commitments in detail over the next 5 years. It is intended, rather, to provide an overview and a focus for collaborative effort between a range of Government Departments and key service providers, both centrally and locally.

This strategy challenges policy makers and service providers to consider the needs of people with dementia in service planning and delivery so that they can continue to participate as citizens and maintain their quality of life.

Definition of Dementia

The World Health Organisation's International Classification of Diseases (1992) describes dementia as:

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

“Dementia” is not a specific disease but is the term used to describe a collection of symptoms caused by a variety of diseases. The most common form of dementia is Alzheimer’s disease, followed by vascular dementia. There are numerous other diseases that can cause dementia including Pick’s disease, Lewy Body disease and AIDS Dementia Complex.

Sometimes a person may appear to have dementia but in fact has a condition that can be reversible, such as depression, a drug reaction or delirium. Some drug treatments only work for a specific disease such as Alzheimer’s disease. In the case of Lewy Body disease, neuroleptic drugs may significantly worsen the symptoms.

It is important that all people experiencing cognitive impairment are referred for medical investigation so that an accurate diagnosis can be obtained and appropriate medication prescribed.

Behavioural disturbances, clinical depression, delusions and/or hallucinations can accompany dementia. It is therefore crucial that a person’s psychiatric state and behaviour are properly assessed and that they have access to specialised treatment when necessary.

Early stages of dementia can lead to loss of confidence, fear of falling and reduced physical capacity (such as reduced muscle strength, gait and flexibility). The person with dementia is at increased risk of falling.

A fall injury is often the first step in loss of independence and often means entry into a residential aged care facility. In addition, people’s lack of confidence and reduced activity, as well as their general change in life circumstances, can lead to depression.

Impact of Dementia

What does having dementia mean for people? It is a very personal journey and every person’s story is unique. What people do share is a need for acceptance by family and friends and continued opportunities to participate and contribute in society within their capabilities.

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

From a participant of the Dementia Advocacy and Support Network, quoted at the National Conference of the Alzheimer’s Association, *Together on a Journey* 27–30 March 2001.

Dementia affects not only the person but also their relationship with their spouse, children, the broader family, friends, acquaintances and people in local communities such as local shop owners. In the case of younger people, work colleagues can also be affected. Dementia has a ripple effect within families. “Partners, sons, daughters, siblings, grandchildren and extended family are all trying to cope with the emotional trauma of losing someone they love, having to adjust to changes in their relationships and sort out the myriad of practical problems associated with providing care or support” (Hampson 2000).

“I did not know what was happening to this man — my husband, my friend, my lover, an essential part of our family life. Once, a very capable man. His memory was poor, his sense of direction deteriorated, his behaviour became erratic and unpredictable. But the greatest shock of all was his diminished intelligence; his inability to plan, to reason, to discuss logically as in the past.”

A carer — Alzheimer's Association NSW

The demanding and intensive nature of dementia places enormous pressures on carers and its particular impact has been well documented (Scofield 2000).

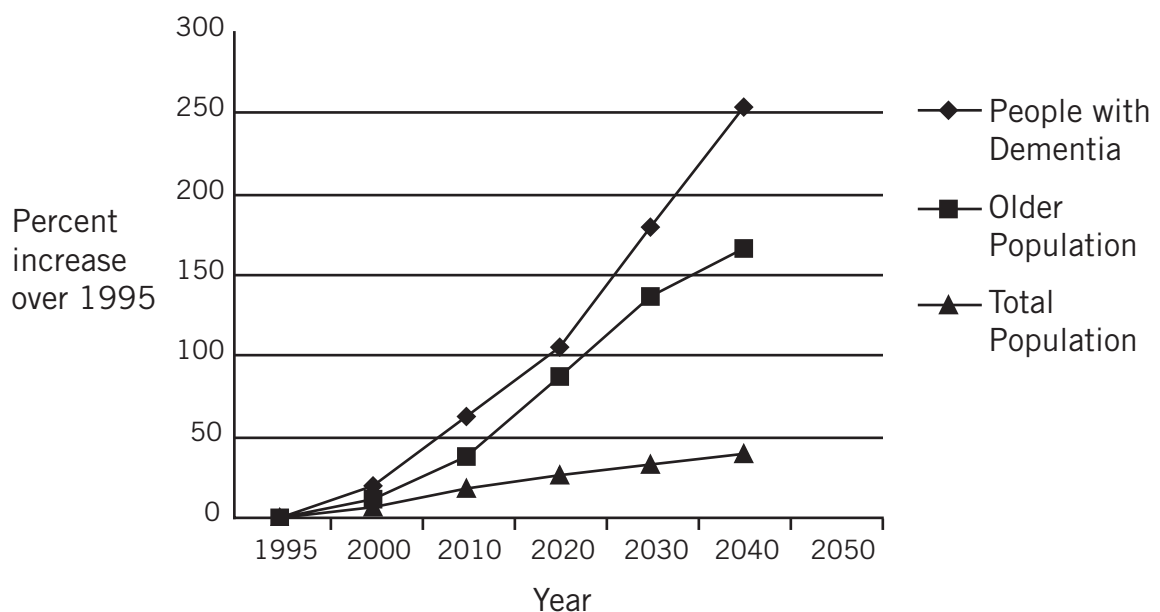
Prevalence

Dementia in Older People

The prevalence (number of cases) of dementia doubles approximately every five years from age 60. Approximately 1 in 20 people over 65 and 1 in 5 over the age of 80 have some form of dementia (Commonwealth Department of Health and Aged Care 2000a).

In the next two decades as our population ages the number of people with dementia in NSW, especially in the oldest age groups, will increase dramatically. The current number of NSW residents with dementia was estimated to be 54,720 in 2001. Projections for Australia indicate this will increase to 64,000 in 2006, 72,960 in 2010 and 91,200 in 2020. In other words, numbers are expected to nearly double by 2020. (See Diagram).

Projected increases in dementia cases, Older Population and Total Population for Australia 1995-2041



Based on Figure 2.1 from report by A S Henderson and A F Jorm, Dementia in Australia, Aged and Community Care Service Development and Evaluation Reports Number 35 Jan 1998 AGPS, Canberra.
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The increasing prevalence of dementia is part of a rising pattern of neurodegenerative diseases that particularly affect older people. The growth in such diseases, which are chronic and disabling, presents a considerable challenge to the health and community care service systems.

Dementia in Younger People

There have been no prevalence studies in Australia for younger people with dementia except one as yet unpublished study on childhood dementia. However, based on prevalence rates from studies in the US there are an estimated 573 people under 60 years of age (Henderson 1998) with dementia in NSW and 1,427 under 65 years of age (Luscombe et al 1998). The actual figures could well vary from this estimate because of trends and regional variations relating to factors like the rise of AIDS in the community, rates of drug and alcohol overuse and the increasing longevity of people with Down Syndrome (Freeth 1994).

The Australian Childhood Dementia Study drew on data from the Australian Paediatric Surveillance Unit — a national scheme for the active surveillance of uncommon conditions in childhood. In this study the prevalence of dementia in childhood (including Rett Syndrome) in Australia was estimated as 5.6 per 100,000 people (Nunn, Williams, Ouvier, forthcoming).

Dementia in People from Migrant Groups

Australia's population is the most linguistically and culturally diverse in the world. It is estimated that in NSW in 2001, 16% of people aged 60 and over are from ethnic communities (Ethnic Affairs Commission of NSW 1999).

There are older people who were displaced after World War 2 from Central and Eastern Europe, who migrated from Southern Europe in the 1960s, or migrated more recently from Asia. Whilst there is no information on the prevalence of dementia in migrant groups in Australia, studies outside Australia have shown that some groups have a lower prevalence and a differing pattern of dementing disease (Henderson 1998).

Carers from diverse cultural and linguistic backgrounds have a lower level of respite and home and community-based services (Scofield 1998). Low usage of services is influenced by factors such as lack of information about available services, language barriers, cultural factors, community expectations and concern over cultural appropriateness of services (Misic 1996, Kratiuk et al 1992).

Access may also be limited by the lack of culturally sensitive diagnostic tools and research in the area of multicultural dementia assessment and delirium assessment. People from diverse cultural and linguistic backgrounds are also less likely to be hospitalised for dementia (McDonald & Steel 1997).

Dementia in Aboriginal People

There is little information on the prevalence of dementia in Aboriginal Australians (Pollitt 1997). There is a widely held view that few Aboriginal Australians develop age-related dementia, such as Alzheimer's disease, due to premature mortality. Aboriginal people experience high mortality rates in adult life and Aboriginal elders are affected more by physical health problems and may suffer distress or depression as well as dementia (The National Consultancy Report on Aboriginal and Torres Strait Islander Mental Health 1995).

As Alzheimer's disease occurs in only a small percentage of the Aboriginal population, dementia prevention for Aboriginal people should take a holistic approach and should include a focus on preventing vascular disease and alcohol-related problems.

It is important to note that many Aboriginal people do not access Aged Care Assessment Teams that undertake dementia assessments, and that the barriers experienced by Aboriginal communities to service access need to be addressed.

People with Dementia in Rural areas

It is assumed that the prevalence of dementia in rural communities is the same as for metropolitan areas. Distance from services can, however, mean that community support and alternatives to hospitalisation are not available. People in these communities can also experience inequitable access to specialised services because of the limited resources available locally. Innovative models of care have been established in rural and remote areas to overcome barriers to service access resulting from issues such as shortages of specialised staff and geographical distance to services.

Stakeholders in the Far West Area Health Service, for example, have established an interagency approach to aged care and are currently reviewing the opportunity provided by Telehealth as a means of accessing Geriatrician services.

People with an Intellectual Disability and Dementia

As people with an intellectual disability are ageing, there is the accompanying increase in age related health concerns, including dementia.

For people with Down Syndrome, there is a particular relationship with dementia. Almost all people with Down Syndrome over the age of 35 develop the plaque and tangle formation in the brain similar to that found in people with Alzheimer's disease. However, as some people with Down Syndrome do not develop dementia, there may be other non-genetic factors involved (Janicki and Dalton 1999).

Australian Context

Overview of Progress

Over the last decade, considerable progress has been made on national and state levels in developing a quality service system for people with dementia. This has been accompanied by increased public awareness of dementia, a greater recognition of the vital role of carers, a greater focus on the needs of people living with dementia as well as their family/carers and a move towards early intervention.

Prevention, Treatment and Cure

While the eradication of Alzheimer's disease or vascular dementia is not imminent, there is a growing sense of optimism that Alzheimer's disease may be a curable disease. There is an ongoing international research effort directed towards the prevention, treatment and cure of Alzheimer's disease.

Another form of prevention is postponing a disease (Jorm 2000). There is an increasing list of possible preventative measures for Alzheimer's disease such as antioxidants, non-steroidal anti-inflammatory drugs, and hormone replacement therapy.

Vascular dementia may be postponed by controlling high blood pressure and lowering cholesterol. Basic health promotion messages such as keeping active, both physically and mentally, and maintaining a good diet may also delay the onset of dementia.

There has also been progress in the development of safer drugs that can slow down the symptoms of Alzheimer's disease and increase a person's functioning. In Australia, drugs that ameliorate the symptoms of Alzheimer's disease have been granted Pharmaceutical Benefits Scheme (PBS) listing. People can now be prescribed these drugs at a subsidised rate, provided that they meet certain improvement criteria.

The availability of these drugs in itself promotes the need for an accurate diagnosis in the early stages of dementia. Earlier diagnosis will give people the opportunity to take advantage of other early intervention strategies such as planning for their financial affairs.

Commonwealth Services and Supports

Following the National Action Plan on Dementia Care 1992–1997 (NAPDC), the Commonwealth Government has continued to provide funding for dementia care. This includes funding to:

- develop respite for carers of people with dementia and challenging behaviour, under the National Respite for Carers Program;
- establish a National Behavioural Advisory Service;
- expand support groups to people with dementia in early stages and their families;
- provide ongoing support for the Dementia Education and Support Program, run through Alzheimer's Associations;
- provide ongoing assistance to rural Aged Care Assessment Teams to assess people with dementia, and
- provide ongoing support for one Psychogeriatric Care Unit in each state. (In NSW, this is the community based Illawarra Dementia Support team).

People with dementia and their families will also benefit from other broader Commonwealth initiatives, such as:

- Community Aged Care Packages;
- the Enhanced Primary Care package that includes new Medicare Benefits Scheme items for health assessments for people aged over 75, care planning and case conferencing;
- the establishment of Commonwealth Carelink Centres to provide a central point of information, and
- the National Training Framework that has established core competencies for aged care workers.

Major challenges remain for the Commonwealth. These include challenges in managing increased demand for both residential care and community care, providing for the cost of upgrading facilities and maintaining the quality of residential care. It is also important that the Commonwealth and State initiatives are integrated with existing state services.

Directions Across Australia

NSW was the first State to develop a dementia plan, the *NSW Action Plan on Dementia 1996–2001*, to complement the National Action Plan for Dementia Care (1992–1997). Victoria and Tasmania have launched new Dementia Plans for 2000 and beyond (Victorian Government Department of Human Services 2000, Tasmania Department of Health and Human Services 1999). South Australia began consultation for their new plan in early 2001.

The Northern Territory will include dementia initiatives in their Aged Services Business Plans and Queensland is developing dementia directions as part of their Strategic Policy Framework for Older People 2000–2004. The Commonwealth Department of Health and Aged Care published their Dementia Policy Framework and Commonwealth Government Initiatives in September 2000 (Commonwealth Department of Health and Aged Care 2000b).

It is expected that future Commonwealth directions for dementia will be included in the National Strategy for an Ageing Australia.

NSW Context

In NSW, a 5-year *NSW Action Plan on Dementia 1996–2001* ended in June 2001. The plan was based on extensive consultation in 1995 with carers, service providers, key interest groups and government representatives, through regional workshops, public submissions and discussion. Key areas addressed in the *NSW Action Plan on Dementia 1996–2001* were:

- information, assessment and diagnosis;
- community support services;
- health care;
- accommodation options;
- protection of the rights and interests of people with dementia;
- community awareness, education and training, and
- policy and planning issues.

The (then) Ageing and Disability Department (ADD) and NSW Health jointly managed the Action Plan which provided a planning framework and strategic directions for funding and service delivery. ADD was responsible for coordinating, monitoring and reviewing the plan.

The NSW Government allocated \$2.2 million for the first 3 years, a further \$300,000 recurrent (\$1.2 million over 4 years) in the 1999–2000 budget and \$150,000 in 2000–2001. More than half the initial funding was transferred to NSW Health to progress its responsibilities under the plan. Recurrent funding under the *NSW Action Plan on Dementia 1996–2001* enabled the establishment of dementia advisory services on the Far North Coast and the Central Coast and an Aboriginal-specific service in the Far West. A Reference Group with representation from government, non-government and consumer organisations worked closely with DADHC and NSW Health to advise on the plan's implementation and priorities (see membership list in Appendix B).

Significant NSW Developments

It is important to recognise that the local Dementia Action Plans are one of many initiatives that have been undertaken by the NSW Government to target chronic illness and that these are complemented by other government initiatives such as the Government's Action Plan for Health, the NSW Care for Carers Program and the Home and Community Care Program.

Home and Community Care Program

People with dementia and their carers are a special needs group within the Home and Community Care (HACC) Program, a joint Commonwealth and State funded program managed by DADHC. There were 23 dementia specific services funded in Rounds 13–16 of the HACC Program (1997–2001), with more than \$2.25 million new funding. An additional \$1.9 million has been allocated to services for people with dementia and their carers in the 2001/2002 HACC State Plan. The HACC Program has also funded the dementia training for HACC service providers under the Dementia Care Learning Program.

Government Action Plan for Health (GAP)

During 1999 the Minister for Health set up two independent bodies. The first, the NSW Health Council (NSW Government 2000) was established to advise on improving the delivery of public health services. The second, the Ministerial Advisory Committee on Health Services in Smaller Towns (Ministerial Advisory Committee 1999) consulted with small rural communities regarding their health and aged care needs and provided recommendations for service delivery models. The NSW Health Department implemented these reports through the *NSW Government Action Plan for Health (GAP)*, which focussed on the organisation and delivery of health services in the areas including: acute care; chronic care; emergency departments; consumer and community involvement in the health system; metropolitan health services, and rural health services.

GAP will inform and influence the development of strategies outlined in *Future Directions*. Specific achievements of GAP for rural areas have incorporated the development of Multi Purpose Services to flexibly address the health and aged care needs of rural and remote communities into the NSW Rural Hospitals and Health Service Program. The needs of people with dementia are also being incorporated into capital service planning for smaller rural hospitals.

A number of GAP Implementation Groups such as the Acute Care and Emergency Service Implementation Groups are developing a focus on aged care that will include services for people with dementia.

NSW Care for Carers Program

The NSW Government has also established the NSW Care for Carers Program, 1999–2003 managed by NSW Health with allocated \$12.9 million funding over 4 years (1999–2003), resulting in \$5.1 million recurrent per annum. The objectives of the program are to:

- provide additional services for carers;
- strengthen existing measures to support carers, and
- promote the broader community's support for carers.

There are 3 priority areas for funding:

- personal supports (including counselling, support groups and education);
- practical supports (including respite and transport), and
- health and community care sector response to carer needs.

The program will target all carers, including carers of people with dementia.

DADHC Planning Framework

DADHC is developing a new *Planning Framework* to enhance the responsiveness of its planning for older people and people with disabilities. The Population Group Planning (PGP) model and the Planning Framework form the key components of DADHC's approach to planning. The PGP model enables planning on the basis of estimated, predicted or reported needs of population groups rather than the attributes of funding programs.

Agencies that are partners in the Memorandum of Understanding on joint planning (NSW Health, Commonwealth Departments of Veterans' Affairs, Health and Ageing and Family and Community Services) are participating in the development of the new framework.

Section 2: Future Directions for Dementia in NSW 2001–2006

Rationale

This strategy has been developed to:

- build on the learning from the projects of the *NSW Action Plan on Dementia*;
- increase the level of integration between health and community care, and
- establish a basic level of service across the state.

The previous plan raised the profile of dementia and increased partnerships and coordinated efforts between a range of government and non-government agencies, both centrally and within local communities.

The goodwill and momentum achieved through the ongoing efforts of the Dementia Reference Group, working groups for specific focus areas, steering committees, individual projects and the development of Area Health Service dementia plans will be maintained and enhanced.

Development of the Strategy

When developing this strategy, DADHC and NSW Health:

- reviewed the strategies of the last plan to develop current priorities;
- consulted on current priorities with key service providers and agencies through two statewide Dementia Forums in 2000;
- incorporated strategies raised at a Dementia and Cultural Diversity workshop;
- consulted on the draft strategy through the Dementia Reference Group, Aboriginal Dementia Working Group, GP Dementia Working Group and two regional workshops, and
- consulted on the draft strategy with DADHC regional offices and Area Health Services.

At the two Forums held in 2000 (one for health providers and one for community providers), a consensus on the priorities for the future included:

- workforce training;
- supporting and enhancing family carers;
- more integration, better targeting, more equitable distribution of services;
- better response to behavioural problems, and
- better treatment in acute care.

Scope

Future Directions for Dementia Care and Support in NSW 2001–2006 comprises a comprehensive and integrated set of strategies to strengthen the service system. It promotes a planned response to the predicted high increase in the numbers of people with dementia and assists in the development of a comprehensive, more equitable service system in NSW.

In implementing this strategy, DADHC and NSW Health will, in consultation with the Dementia Reference Group, focus on:

- providing policy direction;
- developing a statewide overview;
- facilitating dialogue between State and Commonwealth Government on key issues;
- influencing the policy of other relevant state departments;
- supporting local planning around dementia;
- allocating limited funds to consolidating the achievements of the last plan, and
- trialing new ideas.

Services within local communities need to be supported to:

- share resources and expertise;
- clarify referral pathways, improve coordination and strengthen links between services;
- identify local gaps and develop a local plan to improve services, and
- link to existing planning and funding processes.

For significant change to occur, dementia needs to be embraced as a core issue for the range of planning and policy processes that exist in NSW. The challenge is to “mainstream” dementia so that the needs of people with dementia are addressed by the relevant Government Departments, Area Health Services and DADHC regions, by other relevant structures, such as Divisions of General Practice, and by private agencies and individuals.

The term “mainstreaming” dementia refers to efforts to raise the profile of dementia within existing planning and funding streams, rather than meeting the needs of people with dementia wholly within mainstream services. The strategy acknowledges that people with dementia and their carers will require dementia-specific services at various points, in addition to generic services that are sensitive to their needs.

For this reason people with dementia and their carers will continue to be a special target group within the HACC Program.

Objective

The strategy has been designed to maintain the dignity and enhance the quality of life of people living with dementia in NSW.

Goals

The goals of the strategy are to:

- increase awareness of the needs of people with dementia;
- influence policy and funding environments to respond to dementia needs;
- improve access to and quality of community, acute care and residential services and the ability of these services to respond to individual needs;
- enhance the capacity of the health system to respond appropriately to the health needs of people with dementia and their carers, and
- develop a comprehensive and coordinated service system for dementia care.

Guiding Principles

The strategy will be implemented on the basis of the following central principles:

- focus on the individual;
- recognise carers as central;
- respond to diversity;
- facilitate early intervention;
- adopt a public health approach;
- develop partnerships, and
- influence policy and funding environments.

Focus on the Individual

Recognition of the dignity of a person living with dementia is fundamental. There is a crucial need to understand and remain centred on each unique person and their life experiences in order to maintain a person's dignity and quality of life.

Intervention in the past has tended to concentrate on issues around the care of the person with dementia and the essential support of the carer. There is increasing recognition that “we can easily lose touch with the person who is the focus of all this activity” (Sammut 1999). This becomes more challenging as dementia progresses, where language, and in turn effective communication, is lost. This makes it difficult to deal with and understand “difficult” behaviour. Respect for a person's choice is also fundamental. This may include the choice not to act upon the diagnosis. When a person is unable to make their own decisions, effort must be made to take the person's views into consideration and to restrict the person's freedom of decision making and freedom of action as little as possible (Guardianship Act 1987, NSW).

Recognise Carers as Central

Carers have a vital role in maintaining a person's quality of life. More than half of those people with moderate to severe dementia live at home and are able to do so through the support and care provided by families and informal carers, such as friends and neighbours. It is important that the role of carers is recognised, supported and nurtured. Assessments and service delivery need to be made in partnership with carers.

Carers often continue to care for a person with dementia at enormous costs to their own emotional and physical health. As many as 80% of carers of people with dementia have been reported to be suffering from chronic fatigue, depression or anger (Mittleman 1995). It is crucial that carers are supported, not only so that they can continue their caring role, but for their own health and wellbeing.

Respond to Diversity

Recognition of diversity is fundamental to creating equitable access to services for all people with dementia in NSW. Services need to be flexible and address the individual needs of people from diverse cultures, people from Aboriginal backgrounds and the needs of younger people. The particular needs of people in rural and remote areas of NSW have been identified as needing attention.

Facilitate Early Intervention

In the past there has been a pessimistic view of dementia intervention resulting in attitudes such as: “Why find out the person has Alzheimer’s disease if nothing can be done?” However, people with dementia can benefit enormously from early intervention. Early intervention includes early diagnosis, access to information, counselling and support. Early intervention enables people to:

- access medical management which may include clinical treatment such as new drugs that can delay symptoms;
- use techniques and aids that build on individual strengths and help compensate for lost skills;
- benefit from individual support of others experiencing early dementia which may help reduce their sense of isolation and depression;
- have more control over their own life and have the opportunity to discuss and plan their future with significant others;
- put their financial affairs in order, such as assigning an Enduring Power of Attorney, and
- plan for future accommodation and care needs and consider options such as Enduring Guardianship and advanced health care directives.

It is however important to respect individual choice about whether to participate in early assessment and intervention processes. The increasing number of people diagnosed in early stages of dementia has created a new constituency. Services such as peer support groups are being developed to meet their needs and specific information strategies are being targeted to the person with dementia, including websites and consumer-focussed sessions at conferences. These developments are still new and need further expansion. Key agencies need to be able to understand and address the needs of people in early stages as part of their routine response. At the same time, it is acknowledged that the drive for early diagnosis has increased the need for a range of services.

A number of books have been written by people in early stages of dementia. These have provided insight into the experience of living with dementia and have helped to focus efforts on meeting their expressed needs. This development will have longer-term benefits through increased advocacy for people living with dementia and a greater emphasis on their rights.

Adopt a Public Health Approach

It has been widely recognised that dementia needs to be considered through a public health framework. This should include the concepts of prevention, screening, early diagnosis, early intervention and best practice management to maintain function and improve quality of life. The concepts of carer support and healthy ageing are also an integral component to this approach.

As preventative measures or risk factors come to light, it is vital that governments, and the service system, are in a position to respond. It is also important that existing interventions and management strategies are evidence-based or follow good practice models. One priority of this strategy is to disseminate research results and models that have been tested and evaluated and to integrate these into current service delivery.

The other factor important to a public health approach is education to increase health promoting behaviour such as healthy eating and adequate levels of physical activity, both of which are known to reduce the physical decline associated with dementia. Community education strategies to inform people about dementia, the available services and where to seek treatment and support are important components. A public health approach also recognises the role of social factors, such as poverty and social disadvantage in contributing to ill health.

Develop Partnerships

One of the integral messages from the last plan was that responding to needs for people with dementia cannot be limited to a particular department or agency but requires intervention across the service system and at different levels of government. The last plan increased partnerships and coordinated efforts between a range of government and non government agencies both centrally and within local communities. This strategy will build on these developments.

NSW Health and DADHC will continue to work closely in implementing these strategies and in developing partnerships with community organisations and other Departments to promote responsiveness to the needs of people with dementia. For example, NSW Health and DADHC will work towards promoting responses to the needs of people with dementia through the Healthy Ageing Framework and the Home and Community Care Program.

Influence the Policy and Funding Environments

Dementia care will improve if it is recognised as an integral part of business across relevant Government Departments, Area Health Services and key agencies throughout the service system, such as Divisions of General Practice. Dementia care competes with other priority areas for resource allocation.

A key measure of the success of this strategy will therefore be its capacity to influence funding decisions and raise the profile of the needs of people with dementia and their carers within a range of agencies. The May 2001 allocation of \$11.043 million in funding for the next 4 years will build organisational and community capacity to contribute to addressing the complex needs of people with dementia.

Structure

Focus Areas

The plan will cover specific focus areas:

- policy and planning;
- supportive and inclusive communities;
- diagnosis, assessment and management;
- education and training;
- community support services;
- acute care;
- accommodation options, and
- protection of rights and interests.

Focus Area 1: Policy and Planning

Introduction

The dementia care system in NSW is complex, with a range of funding arrangements and variation in the amount and type of service delivery within local communities. Several Commonwealth and State Departments have a role in funding dementia support, and consequently there are a number of boundary issues that impact on continuity of care or access to services. It is crucial that State and Commonwealth Departments collaborate to clarify roles and responsibilities. One such priority area for collaboration is the provision of community and residential psychogeriatric services.

Important first steps in the central planning process include mapping current service provision and funding sources in NSW, reviewing the adequacy of data sets, identifying key elements required for effective dementia care and developing recommended service profiles.

There is a clear need for the data currently collected to more accurately reflect the impact of dementia on the health system. For example, delirium presents in over 50% of older people requiring acute hospitalisation and dementia is a contributing factor in admission for at least half of these (Moran and Dorevitch 2001).

Planning for dementia also needs to be strengthened at the local level. Local planners and service providers are well positioned to identify service gaps and respond to specific dementia needs through a local implementation plan. The development of local dementia-related service networks can also help clarify referral pathways and identify opportunities to share resources, from educational and professional expertise to building use.

Achievements under the *NSW Action Plan on Dementia 1996–2001*

From a policy and planning perspective, the *NSW Action Plan on Dementia 1996–2001* was successful in a number of ways:

- It provided a policy framework for agencies in NSW and raised the profile of the needs of people with dementia;
- It provided a framework and impetus for Area Health Services to develop Area Dementia Plans. In some areas, this brought together the range of local services, which helped to coordinate strategies and highlight service gaps. This planning exercise also highlighted the lack of clarity about local funding and the need for dementia-specific resource allocation, and
- provided a focus for the establishment of a Reference Group and working groups such as the Community Education, General Practitioner and Aboriginal Working Groups to ensure that implementation of the plan was based on expert advice and was responsive to current needs.

Future Aims

The following aims are identified for this focus area:

- 1 Develop a public health approach to dementia that encompasses the concepts of prevention, early intervention, healthy ageing, and evidence-based practice in order to maintain function and improve quality of life;
- 2 Strengthen local planning and service development;

- 3 Recognise and support the central role of carers in maintaining function and quality of life for people with dementia and provide appropriate supports for carers;
- 4 Influence state and national policy and planning processes to address the needs of people with dementia, and
- 5 Develop an equitable and coordinated system of dementia care in NSW.

Appendix A outlines specific strategies for 2001–2003.

Focus Area 2: Supportive and Inclusive Communities

Introduction

The general awareness and attitudes of the wider community towards dementia are important factors that influence any individual's understanding of dementia and contribute to the sense of support or isolation felt by the person with dementia and their family.

A supportive community enables a person living with dementia to participate and live as normal a life as possible and for families to be supported. Community awareness strategies should promote the advantages of early action, convey a positive image of people living with dementia, and inform people where to get help and how to respond to and assist people with dementia and their families.

One of the most common concerns of individuals and communities when they consider longer lifespans is increased likelihood of having dementia (Huppert 2000). Community awareness strategies should reassure and empower older people at the same time as alerting people to when they should seek further help.

In NSW, dementia awareness varies considerably across the population. Developing partnerships between ethnic communities and service providers and increasing the number of bilingual workers with dementia expertise are important strategies for promoting awareness of dementia and available services. Dementia is an emerging issue for people in Aboriginal communities. Further consultation is needed to identify the extent and experience of dementia, current issues and effective strategies in Aboriginal communities.

Achievements under the *NSW Action Plan on Dementia 1996–2001*

Many strategies including research into community attitudes, raising community awareness, the development of culturally-specific strategies and translated materials, and assisting services to be more culturally appropriate have helped to increase knowledge of, and change community attitudes towards, dementia.

Future Aims

The following aims are identified for this focus area:

- 1 Increase awareness of dementia and available services;
- 2 Address the specific needs of Aboriginal communities;
- 3 Improve awareness of dementia amongst diverse cultures in NSW, and
- 4 Promote more supportive and inclusive community environments.

Appendix A outlines specific strategies for 2001–2003.

Focus Area 3: Diagnosis, Assessment and Management

Introduction

General Practitioners (GPs)

GPs are often the first point of contact for many people with memory loss or for family members concerned on another person's behalf. GPs can play a central role in diagnosis and ongoing management of people with dementia.

However, as there is considerable variation in the skills of GPs in the diagnosis, involvement of carers and their links to ACATs and other support services, it is essential that training and support for GPs be provided. Enhancing the role of the GP as the primary health care provider for people with dementia and their carers remains a crucial issue (Paley et al 2000).

The introduction of the enhanced primary care (EPC) MBS items for health assessments, care planning and case conferencing has potential to support GPs in detection, assessment, management and referral of people with dementia.

The employment of practice nurses can reduce the workload of GPs and increase the assessment of activities of daily living (ADLs). The availability of pharmacological treatment may also assist GPs to detect and respond to memory loss. The Commonwealth Carelink Centres established in 2001 should assist GPs in making referrals to appropriate services.

It is important that diagnosis and ongoing management is a partnership with the person, the person's family, specialists and other support services. It is also crucial that GPs are able to link with the expertise of geriatricians, psychogeriatricians and neurologists when they are uncertain of the diagnosis or where there are serious neuro-behavioural complications. Access to specialists is an issue for people in some rural and remote areas.

GPs must be vigilant to the needs of carers of people with dementia as they have been shown to have poorer health and impaired immune function as well as higher levels of emotional distress compared to other carers (Brodaty 1994).

Aged Care Assessment Teams (ACATs)

ACATs have expertise in the assessment of people with dementia. ACATs receive core funding from the Commonwealth for assessment services as well as funding in rural areas for dementia support and assessment. Many ACATs are integrated into existing State-funded geriatric services. When this occurs, ACAT members are often part of a multidisciplinary team that can provide a comprehensive service, such as diagnosis at memory clinics, counselling and support through dementia support workers, psychogeriatric expertise, ongoing case management, and follow up and assistance with residential care choices. ACATs are also increasingly involved in issues of guardianship and responding to elder abuse.

It is the State component of their funding which determines the ability of ACATs to take on the broader roles. Variations in funding for ACATs have arisen as a result of historical circumstances, the efforts of key individuals at the regional level to attract funding and priorities within Area Health Services (NSW Office On Ageing 1995).

ACATs need to be supported to maintain their leadership role in dementia assessment and to develop their skills in the ongoing management of people with dementia. With the increased recognition of dementia in Aboriginal communities and the difficulties for people from diverse cultures in accessing services, ACATs need to consider strategies for targeting these groups.

Comprehensive Assessment in Community Care

While ACATs and GPs are key players in the assessment process, other community service providers are also involved. The 1999 Targeting study by Dr Anna Howe (National Ageing Research Institute and Bundoora Extended Care Centre, 1999) identified 3 distinct groups of HACC consumers. Whilst the vast majority (80–85%) need only one or a small number of support services, the remainder require multiple or more intensive services in response to complex needs.

As part of national reforms of assessment in the HACC Program and additional requirements in NSW, local protocols for a single comprehensive assessment process are being developed. Consumers with complex needs will be referred to a locally endorsed Comprehensive Assessment Service to develop a care plan. Other current initiatives, such as Veteran's' Home Care, Community Aged Care Packages, and the EPC initiatives have the potential to be linked to these reforms. It is important that dementia assessment and management are incorporated into these new initiatives.

Carers

It is often a person's spouse or carer who raises the initial concerns about memory loss or personality changes and the carer's observations are an important part of the assessment process. As mentioned previously, carers enable a person to remain at home but living with and caring for a family member can have profound adverse effects on the mental health of carers. Long-term support, individual and family counselling and support group participation can have a positive impact (Mittleman 1995).

People Who Live Alone

Because the symptoms of people without a spouse or carer are less likely to be drawn to the attention of service providers, strategies for early assessment need to target those living alone.

Challenging Behaviour and Behavioural Disturbance

A significant number of people with dementia develop behavioural disturbance and their behaviour becomes "difficult" to manage over the course of their illness. Prevalence figures are available but are hard to compare because there is no consensus on classification (Bird 1998). This behaviour has been given various labels such as "challenging behaviour" or "behaviours of concern". The terms usually refer to behavioural disturbance exhibited in forms such as aggression, screaming and shouting, inappropriate sexual behaviour, restlessness and agitation, intrusiveness and resistance to care.

These behaviours and symptoms can cause considerable distress to family members. The behaviour often excludes the person from much needed respite or permanent care. Many of these behaviours or symptoms are short lived and can be overcome through appropriate diagnosis, counselling, medication, treatment, environmental adjustments and developing understanding by families and service providers about the person and the behaviour.

A person with dementia may develop a psychiatric illness such as depression or psychosis. Similarly, people who have a primary psychiatric condition may develop dementia. These people often have few support networks, are difficult to place in residential facilities and present particularly challenging behaviours. Services also raise issues about people with frontal cognitive impairment but intact memory whose uninhibited behaviour or poor judgement causes difficulties before a formal diagnosis is made.

The establishment of an effective interface between specialist mental health services for older people, primary care and aged care services is critical to ensure appropriate clinical assessment (including differential diagnosis), management and coordination of care for people with dementia and mental health conditions. Specialised assessment, diagnosis and behaviour management can be provided on a consultation-liaison basis through psychogeriatric services for those people who have severe behavioural difficulties and behavioural disturbance that require specialised intervention.

Partnerships between psychogeriatric services, primary care and aged care services need to be fostered in addition to the development of models of care that encompasses behavioural assessment and diagnosis, short term accommodation or intensive support for severe behavioural disturbances.

As problems in behaviour management can result in people with dementia presenting at hospital Emergency Departments, it is important that Emergency Departments establish links with psychogeriatric services and that the skills of triage and Emergency Department staff around dementia care are enhanced.

Dementia and Intellectual Disability

As people with intellectual disability age, appropriate diagnosis, assessment and management of dementia is an emerging, complex issue. Some people with an intellectual disability have their dementia diagnosed late; others are 'misdiagnosed' or presumed to have dementia because they exhibit a decline in function whereas they may have another treatable condition. Families caring at home for someone with an intellectual disability may be significantly affected by a "second disability diagnosis" and need access to information, counselling and support.

There is also a need to introduce standard screening for people who are clients of the disability services system once they have reached a specified age and a standard pathway for referral to a specialist if indicated. This would include guidance about the range of screening and assessment tools that are available and the need for clear documentation over time about a person's level of functioning to assist specialist diagnosis and assessment.

These strategies are in line with the guidelines and recommendations of the Edinburgh Principles adopted by the International Association of the Scientific Study of Intellectual Disability (IASSID) (Wilkinson and Janicki 2001).

Achievements under the *NSW Action Plan on Dementia 1996–2001*

Achievements include the establishment of dementia advisory services in the Far North Coast and Central Coast, and an Aboriginal-specific service in the Far West; the inclusion of dementia awareness training for health care interpreters in their core curriculum; the development of a validated multicultural screening instrument; strategies to create links between General Practitioners and Aged Care Assessment Teams; the development of Guidelines for GPs, management strategies for dementia and challenging behaviour, and skills enhancement courses for GPs.

Future Aims

The following aims are identified for this focus area:

- 1 Provide equitable access to early diagnosis, appropriate assessment, timely information and short term counselling on diagnosis and at key stages, and referral to support services;
- 2 Improve the detection, diagnosis, assessment and management of people with an intellectual disability and dementia;
- 3 Continue to support GP skills development in early diagnosis, assessment, management and referral to support services;
- 4 Continue to support ACATS in their assessment role with people with dementia;
- 5 Improve GP links to ACATs, community services and residential care;
- 6 Promote the involvement of carers in care decisions;
- 7 Provide equitable access to behavioural advice for carers, community support services and residential care facilities to manage challenging behaviour;
- 8 Reduce the current complexity of the service system for people with dementia, and
- 9 Enhance workforce skills in diagnosis, assessment and management in targeted, critical areas.

Appendix A outlines specific strategies for 2001–2003.

Focus Area 4: Education and Training

Introduction

Workforce training and education is a crucial component of quality care. Dementia care should be provided by staff who understand dementia and can respond appropriately.

Care takes place in a variety of settings such as hospitals, day centres, residential care and in the home. The challenge is to appropriately match workers' knowledge, skills and qualifications with the care needs of people with dementia in settings that experience high staff turnovers and recruitment difficulties, and support them in their provision of quality care.

Currently both the public health and aged care systems are experiencing difficulties in recruiting nursing staff. As Registered Nurses, Enrolled Nurses and Assistants in Nursing are key members of the workforce that provide dementia care in these systems, these issues require attention.

The Commonwealth Government introduced competency-based training as part of its National Training Framework. The Community Services Training Package (CSTP) is the Vocational Education and Training (VET) package for the community services industry.

The CSTP has the potential to better address the training needs of HACC and disability services through tailored training to meet workforce needs including on-site training and customised training materials. Competency-based training provides an incentive for workers by acknowledging prior learning and linking to nationally recognised qualifications.

Increased opportunities for dementia education for health professionals at undergraduate and postgraduate level and in the workplace will contribute to high quality dementia care. People with dementia also have contact with workers from a range of agencies in the course of their daily life such as staff in banks and public transport staff. These workers can benefit from dementia-specific in-service training.

Carer education is another important area to be addressed as research has shown that training can reduce carer stress and delay movement to residential care (Brodaty 1989). Training should focus on increasing carer knowledge and skills, for example, in risk management in the home, particularly where confusion is accompanied with high levels of mobility.

Many dementia training materials and resources have been developed in Australia and need to be collated and disseminated widely. Staff of disability services need information and training to assist them to provide appropriate support to people with an intellectual disability and dementia. Family carers also need information about the impact of dementia on people with an intellectual disability.

Achievements under the *NSW Action Plan on Dementia 1996–2001*

Education and training needs were addressed through various strategies such as the development of a training resource for Continuing Legal Education, a statewide dementia awareness training project for Aboriginal HACC and Health workers, and a training project for public contact staff in a range of government and private sector settings.

Future Aims

The following aims are identified for this focus area:

- 1 Improve access to dementia training for critical sections of the NSW workforce, including community, residential and acute care staff;
- 2 Ensure that training promotes understanding of the person living with dementia, and the crucial role of family carers, and encourages the trainee to maintain their dignity and enhance their quality of life;
- 3 Support GPs' access to dementia education to improve diagnosis, management and referral, and
- 4 Increase carer access to education.

Appendix A outlines specific strategies for 2001–2003.

Focus Area 5: Community Support Services

Introduction

Families and other informal carers provide the majority of care for people with dementia and it is this support which enables people to remain at home as dementia progresses.

Informal care is complemented by more formal support through the joint Commonwealth and State Home and Community Care Program (HACC), through the Veterans' Home Care Program (VHCP) and through the Commonwealth Community Aged Care Packages (CACPs).

HACC provides home care, personal care, respite, transport and more intensive support for people with complex needs through the Community Options program. As people with dementia are a special needs group in HACC, dementia specific respite care, community options and monitoring services are funded through the HACC Program. These services can also assist an increasing number of people with dementia who live alone to continue to live independently by providing ongoing monitoring and coordination of services as well as appropriate medication management.

The VHC Program provides domestic assistance, personal care, home and garden maintenance and respite care for veterans and war widows/widowers. CACPs usually provide a variety of services through the same worker and are particularly suited to people with dementia. The number of multicultural and ethno-specific CACPs is increasing.

Research both in Australia and overseas has shown that respite is highly valued by carers (Shanley 2001). However, it is important that respite is available at appropriate times, provided by people who understand the person's condition and support requirements, and benefits the person being cared for (Rossiter 1993). Access to a variety of services and community programs is likely to benefit a person with dementia, for example, access to gentle exercise programs.

Other issues include the need for flexible and responsive services and access to dementia training for community care staff. The issue of staff recruitment problems is particularly significant in small rural and remote areas. The disability services system is generally not geared to dementia care either in terms of staffing levels, dementia-appropriate environments and staff skills. When a person's care needs increase, disability services are not always able to respond and aged care services may not be accessible or offer appropriate care. There is a need for dementia training for disability services staff, information for families, and new service options to ensure that people with an intellectual disability and dementia are appropriately supported.

Achievements under the *NSW Action Plan on Dementia 1996–2001*

Achievements included the development of publications for carers and for service providers as well as the identification of strategies for improving service response to younger people with dementia.

Publications included a practical manual on how to modify the home environment for a person with dementia, a manual on the use of telephone support groups for isolated and geographically dispersed carers, and a manual for service providers and planners to encourage the development of more flexible respite for people with dementia.

Future Aims

The following aims are identified for this focus area:

- 1 Improve access to information, education, employment assistance, counselling and peer support for people in early stages of dementia and those with early onset;
- 2 Continue to expand the availability of a range of community support services for people with dementia;
- 3 Recognise and support carers of people with dementia, and
- 4 Improve access to consultative expertise on the management of challenging behaviour for community support services and family carers.

Appendix A outlines specific strategies for 2001–2003.

Focus Area 6: Acute Care

Introduction

People with dementia experience the full range of acute illnesses that require hospitalisation. Hospitals are focused on providing efficient and effective treatment for acute illness and often the particular needs of people with dementia are not addressed well.

People with dementia can experience difficulties in the initial response in emergency departments, individual care environments, detection of delirium, compliance with treatment and in discharge planning. Patients with dementia currently have a length of stay that is four times greater than patients without dementia and their casemix complexity is almost double that of other patients (CDHAC 2000c).

Strategies are needed to improve the detection and management of delirium and dementia from Emergency Departments, admission, discharge planning and linkages to community care. The current physical environments of many hospitals do not support effective management for people with dementia and delirium and there is increasing recognition of the need for separate wards to effectively treat people with challenging behaviour.

While strategies are needed to prevent inappropriate admissions and to offer treatment outside hospitals, strategies that promote early discharge and strengthen support in the community also require exploration and, where appropriate, collaboration at the State/Commonwealth level. NSW Health has supported local priorities for action under chronic and complex initiatives in the *NSW Government Action Plan for Health*. It will be important to integrate dementia initiatives into existing and future initiatives in this area.

Achievements under the *NSW Action Plan on Dementia 1996–2001*

A key initiative was the development of a Better Practice Model for the Hospital Care of People with Dementia, jointly funded through the NSW Action Plan on Dementia and Southern Cross University.

Future Aims

The following aims are identified for this focus area:

- 1 Improve dementia diagnosis and management in public hospitals, including management of challenging behaviour;

- 2 Make hospital settings more appropriate for people with dementia;
- 3 Develop alternatives to hospital admission, when appropriate, and
- 4 Ensure that the needs of people with dementia and their carers are incorporated into discharge planning.

Appendix A outlines specific strategies for 2001–2003.

Focus Area 7: Accommodation Options

Introduction

While the majority of people with moderate to severe dementia remain in the community, a significant proportion live in residential care.

The presence of dementia has been found to double the likelihood of a person being recommended to enter a low care facility and triple the likelihood of admission to a high care facility compared to older people with other diagnoses (Department of Human Services 1997). Key precipitating factors include physical dependence, irritability, nocturnal wandering and incontinence (Eccles et al 1998). Approximately 60% of nursing home residents and 28% of hostel residents have some level of dementia (Commonwealth of Australia 2000). Dementia care therefore needs to be recognised as an integral component of the residential care system. Across NSW there are approximately 50,000 Commonwealth funded beds in residential care facilities that are open to provide care to elderly residents. These are mostly operated by the non-government sector with NSW Health operating approximately 2000 residential aged care beds. In addition, NSW Health funds 9 Confused and Disturbed Elderly (CADE) units which provide residential care for people with dementia and other problems and/or confusion. There are also some people with dementia in small rural hospitals as long-term residents.

In 2001 a discussion paper was released by the NSW Department of Health putting forward a number of proposals for improving the interface between the aged and acute sectors care in NSW. Under the proposal, older people with dementia who may have previously been cared for in a CADE unit would be cared for in Commonwealth funded aged care facilities. NSW Health and the Commonwealth could then develop a comprehensive dementia specific support system for older people with dementia in aged care.

The NSW Department of Health is reviewing the proposal to make sure that the issues raised by the community and industry are accounted for in developing a comprehensive service for older people with dementia. The decision to seek placement in a residential aged care facility is a difficult one and families need information and support in making the selection and the transition.

ACATs and GPs play a critical role in supporting families. Carers who are particularly vulnerable at this time are older spouses who have no family to assist, people with limited or no English, and carers with health problems or limited respite to do the searching for residential care (Department of Human Services 1997). While residential care reduces the physical demands on carers, it does not reduce the emotional stress carers feel. Carers have ongoing support needs. Many remain involved in the care of their relative following placement in residential care and the resident can benefit considerably when residential care staff form partnerships with carers.

The majority of placements to residential aged care facilities are referred from acute care facilities. This process often requires an urgent response and severely restricts choice. Carers report difficulties in finding a residential aged care facility that has the appropriate staff skills and physical environment, especially if a person is ambulant and has challenging behaviour. Those facilities that do accept people with challenging behaviour report the lack of back up support and advice when they have difficulty managing the person's behaviour. Inappropriate use of medications and other forms of restraint remain a significant issue. This indicates that there is scope for a focus on psychogeriatric issues in residential aged care facilities including training staff to manage dementia and challenging behaviours and considering appropriate environments when planning facilities.

Current funding arrangements for residential care in Australia tend to encourage the provision of care in large facilities. This contrasts to other countries such as Sweden and Finland where people with dementia are cared for in small suburban houses (CMHC 1999). There is increasing acceptance that segregation of residents with dementia from other frail residents can be beneficial for both groups.

Segregation in wings or sections can reduce intrusive behaviour, enable facilities to tailor staff rosters and activities to the needs of residents with dementia and provide safer and more secure environments. However, introducing person centred approaches to care is dependent on the attitude and leadership of management (Rosewarne 2000).

While residential facilities cater for older people, with almost half of residents aged 85 years and over, it is often the only supported accommodation option for younger people with dementia. The need to explore more appropriate options is an issue requiring further collaboration with the Commonwealth Department of Health and Ageing. Residential care for people from culturally and linguistically diverse backgrounds is provided in both ethno-specific and mainstream residential aged care facilities. The development of clusters has enabled such facilities to offer more culturally appropriate care.

Aboriginal elders who are in need of care prefer care in their own communities so that they can be with families and kin, and die on their own land (Swan and Raphael 1995). Whilst Aboriginal people are placed in mainstream facilities in order to remain near their communities, Aboriginal-specific residential facilities are available in NSW such as Rose Mumbler in Nowra and Booroongen Djugun in Kempsey. The Commonwealth also funds flexi care services designed to allow Aboriginal people with care needs to remain in their own communities.

Many people with an intellectual disability and dementia live in disability services that are not designed to provide appropriate dementia support and there is anecdotal evidence that access to mainstream aged care can be a problem. A range of accommodation and service options for this group of people should be developed and tested, in order to find a way to link disability services, dementia care and palliative care.

GPs play a vital role in the assessment and management of people with dementia in residential care. There is continued debate as to whether geriatric and psychogeriatric primary care is a skill that should be formally recognised or whether a limited number of GPs should be accredited to each facility, as recommended by Draper (1999). The MBS items for care planning have now been extended to GPs for residential care. There is also the recommendation that residential facilities establish medication advisory committees (NSW Health 1997) and utilise the expertise of local pharmacists.

Achievements under the *NSW Action Plan on Dementia 1996–2001*

Achievements included a project researching the accommodation needs of younger people, publication of design manuals for rural hospitals and aged care facilities and the development of help sheets for carers on residential care.

Future Aims

The following aims are identified for this focus area:

- 1 Promote strategies to maintain independence and safety of people with dementia living at home including strategies to maintain healthy lifestyles;
- 2 Develop appropriate accommodation options for people with dementia, including care of people with challenging behaviour, younger people and people with an intellectual disability and dementia;
- 3 Increase the capacity of mainstream residential care facilities to respond to the needs of people with dementia including people with challenging behaviour, and their carers;
- 4 Improve access to appropriate residential care for people in rural areas, and
- 5 Improve access to appropriate care for people from culturally and linguistically diverse backgrounds.

Appendix A outlines specific strategies for 2001–2003.

Focus Area 8: Protection of Rights and Interests

Introduction

People with dementia gradually lose their ability to make decisions about their own financial and personal affairs. Eventually, a person is unable to carry out or make decisions about many aspects of daily living and is dependent on others for care and for the protection of his or her rights. Most people with dementia are cared for by family members who take on the responsibility for decision-making on an informal basis.

Formal arrangements for substitute decision making such as guardianship or financial management orders are usually only introduced when the informal arrangements no longer work, if there is disagreement over decisions being made or if the person is in need of protection from abuse, exploitation or in an unsafe situation.

With the increase in earlier diagnosis, there is increasing opportunity for people in early stages to plan ahead and to ensure that their financial, lifestyle and health care choices are known in advance. People who are diagnosed in early stages of dementia are still able to make decisions and are able to appoint an Enduring Power of Attorney, Enduring Guardianship and to complete an advanced care directive. Planning for future decision making is one of the most important actions that can be taken to reduce anxiety, confusion, family conflict, untimely loss of independence, and conflict with services providers (Department of Human Services 1997).

People with dementia are particularly vulnerable to financial abuse and caregiver neglect (Weeks 1997). Strategies to alleviate carer stress are not only important in their own right but may also assist in the prevention of abuse. People with dementia in residential care and other supported accommodation are also vulnerable, as they are dependent on others to protect their interests and rights. Carers are often called on to make complex and difficult health care decisions especially at the end stages of dementia.

Achievements under the *NSW Action Plan on Dementia 1996–2001*

Achievements included legal issues forums; Dementia Awareness in Law Week 2000; a Planning Ahead for Older People project to increase opportunities for older people to be better informed about options such as Enduring Power of Attorney, Enduring Guardianship and advanced health care directives; and a Dementia Awareness Project for lawyers.

Future Aims

The following aims are identified for this focus area:

- 1 Increase access for people in early stage dementia to information and opportunities for planning ahead options and substitute decision making for their future financial, health and lifestyle needs;
- 2 Introduce mechanisms to further protect the rights and interests of people with dementia;
- 3 Support families involved in decisions regarding clinical management in final stages, and
- 4 Increase access to palliative care for people with dementia in final stages.

Appendix A outlines specific strategies for 2001–2003.

Conclusion

NSW is well placed to develop and deliver effective and quality services and systems for people with dementia, their families, carers and service providers. The NSW Government will achieve positive outcomes by implementing a range of strategies such as strengthening partnerships and linkages between services, providing targeted training to service providers, promoting good primary health care, recognising and supporting the valuable work of carers, and working towards early intervention.

NSW Health and DADHC will continue to work together across the eight focus areas over the life of this strategy to achieve the best service system possible to address the needs of people living with dementia in NSW.

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Appendix A: Strategies for 2001–2003

Focus Area 1: Policy and Planning

Funding Years 1 & 2 \$1,298,000

| Strategies | Lead Agency |
|--|---------------------|
| DADHC will fund planning and service development strategies in each DADHC local planning area to assist with identifying and responding to local dementia needs and with improving the coordination of health, community and residential services at the local level. | DADHC |
| NSW Health will fund two pilot Primary Dementia Care Network partnership projects to develop and implement strategies to resolve gaps in service provision and promote responses to dementia needs in local planning processes. | NSW Health |
| DADHC will fund an initiative to improve data collection through the Dementia Advisory Services. | DADHC |
| DADHC will establish a State–Commonwealth Interdepartmental Working Group to oversee the policy and planning initiatives of <i>Future Directions</i> . The Working Group will oversee strategies including: <ul style="list-style-type: none">• coordinating the mapping of local dementia services;• developing a dementia service planning framework to guide planning, resource allocation and service development at the local level;• reviewing the usefulness of current data collections and facilitating identified improvements;• identifying and clarifying key boundary issues for dementia care and facilitating resolution, and• evaluating Future Directions. | DADHC |
| DADHC and NSW Health will support the dissemination of <i>Future Directions</i> , outcomes of projects, wider dementia research and good practice models. | DADHC NSW Health |
| DADHC and NSW Health will fund a Senior Policy Officer position in each Department to implement <i>Future Directions</i> . | DADHC NSW Health |

Focus Area 2: Supportive and Inclusive Communities

Funding Years 1 & 2: \$495,000

| Strategies | Lead Agency |
|---|---------------------|
| DADHC will establish a Community Awareness Working Group to identify strategies to build on previous successful initiatives. | DADHC |
| DADHC will fund further awareness strategies following advice from a Community Awareness Working Group. | DADHC |
| NSW Health will fund community awareness initiatives with a health promotion focus, in liaison with the Community Awareness Working Group. | NSW Health |
| NSW Health and DADHC will both fund community awareness strategies for diverse communities including strategies targeting bi-lingual GPs, following advice from the Community Awareness Working Group and GP Working Group. | DADHC NSW Health |
| NSW Health will support an Aboriginal Dementia Working Group to provide advice and direction on strategies relating to dementia and Aboriginal people under <i>Future Directions</i> . | NSW Health |
| NSW Health will develop strategies for Aboriginal communities following community consultation to better understand the extent and experience of dementia and advice from the Aboriginal Dementia Working Group. | NSW Health |

Focus Area 3: Diagnosis, Assessment and Management

Funding Years 1 & 2: \$1,505,000

Strategies

Lead Agency

DADHC will increase the number of dementia advisory services across NSW to respond to the needs of all people with dementia including people in early stage dementia, younger people with dementia, people from culturally diverse backgrounds, Aboriginal people and people in rural and remote areas.

DADHC

DADHC will support the development and implementation of guidelines for disability service providers on assessment of people with intellectual disabilities and dementia, following workshops with key experts.

DADHC

NSW Health will improve the availability of age-appropriate information for younger people with dementia.

NSW Health

NSW Health will support a General Practitioner Working Group to provide advice and direction to progress the general practitioner-related strategies under *Future Directions*.

NSW Health

NSW Health will foster partnerships between GPs and ACATs, specialists, mental health services for older people, local aged care services and dementia advisory services in assessment and management, utilising the Enhanced Primary Care case conferencing and care planning items, following advice from the GP Dementia Working Group.

NSW Health

NSW Health will develop appropriate strategies and initiatives to improve access to behavioural advice and management for people with dementia and challenging behaviours (including those with dementia and mental health conditions) following piloting of potential service models.

NSW Health

Focus Area 4: Education and Training

Funding Years 1 & 2: \$315,000

Strategies

Lead Agency

DADHC will establish a Dementia Training Working Group to determine the key components of the NSW workforce that require dementia training and develop a strategic plan to facilitate coordinated, equitably targeted training.

DADHC

DADHC will fund the placement of a directory of training materials on relevant websites in liaison with ITAB.

DADHC

NSW Health and DADHC will each fund a project to progress the training strategic plan.

NSW Health
DADHC

DADHC will assist HACCC service providers to identify their dementia training needs and to meet their needs through the National Training Framework.

DADHC

DADHC will support public contact agencies to identify their dementia education needs and contribute to innovative training projects.

DADHC

NSW Health will develop and implement strategies to enhance coverage of dementia in training programs for health professionals, including management of challenging behaviour, in consultation with relevant professional organisations and educational institutions.

NSW Health

NSW Health will support regular forums to provide education, information exchange and feedback on *Future Directions*.

NSW Health

Focus Area 5: Community Support Services

Funding Years 1 & 2: \$322,000

Strategies

DADHC will support local planning areas to develop strategies to improve access for people with dementia to a range of respite care options, following on from the local Dementia Respite Workshops.

DADHC and NSW Health will develop and implement strategies to increase participation of people with dementia in mainstream leisure activities.

DADHC will scope and test the availability of employment assistance for younger people with dementia and facilitate access.

Lead Agency

DADHC

DADHC
NSW Health

DADHC

Focus Area 6: Acute Care

Funding Years 1 & 2: \$1,100,000

Strategies

NSW Health will establish a Dementia Acute Care Working Group from relevant units in NSW Health and with Area Health Service representation to provide advice on the implementation of acute care strategies.

Lead Agency

NSW Health

NSW Health will develop and implement acute care strategies, following advice from the Acute Care Working Group.

NSW Health

These strategies will include:

- a dementia training strategy for acute care staff (including training on delirium);
- protocols for dementia diagnosis and management (including management of challenging behaviour associated with dementia);
- guidelines for Emergency Departments;
- admission and discharge protocols;
- design guidelines;
- alternatives to hospital admission, and
- integration of dementia initiatives into existing chronic and complex care strategies.

NSW Health will fund 10 Dementia Clinical Nurse Consultant positions across NSW to improve acute care (including staff training and behavioural advice and management) for people with dementia.

NSW Health

Focus Area 7: Accommodation Options

Funding Years 1 & 2: \$545,000

| Strategies | Lead Agency |
|---|-------------|
| DADHC will update information in <i>At Home with Dementia</i> , including new advances for people living alone and provide workshops for key service providers. | DADHC |
| DADHC will research the range of accommodation models currently available for younger people with dementia, including younger people with dementia and intellectual disability. | DADHC |
| Following research, DADHC will fund strategies to improve access to appropriate accommodation options for younger people with dementia. | DADHC |
| In liaison with the CW Department of Health and Ageing, DADHC will promote improved advice to residential care providers on design and care practices for people with dementia. | DADHC |

Focus Area 8: Protection of Rights and Interests

Funding Years 1 & 2: \$220,000

| Strategies | Lead Agency |
|---|--------------------|
| DADHC will implement further educational strategies for protecting the rights and interests of people with dementia, following advice from the Planning for Later Life Forum. | DADHC |
| NSW Health will develop protocols and educational strategies on substitute consent and advanced health care directives. | NSW Health |
| NSW Health will research and develop resources for workers and families on palliative care and dementia. | NSW Health |

**Total Funding
for
*Future Directions for Dementia Care
and Support in NSW 2001–2006*
Years 1 & 2: \$5,800,000**

Appendix B: NSW Dementia Reference Group

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(Members as at January 2002)

