

# Dementia Framework for Victoria, 2005 and Beyond Consultation Paper

Victorian Dementia Reference Group  
Aged Care Branch  
Department of Human Services  
December 2004

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A Consultation Paper on the Dementia Framework for Victoria, 2005 and Beyond.

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### **Acknowledgements**

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# Contents

Purpose of this Consultation Paper	1
Dementia	3
Victoria's Record of Achievement in Dementia Policy and Practice	4
Dementia and the Changing Demographics of Victoria	7
Opportunities for Future Action in Dementia Policy and Practice	12
Overview - Dementia Policy and Practice 2005 and Beyond	15
Suggested Strategies 2005 and Beyond	
A. Preventing and reducing risks of dementia - healthy and active living	18
B. Early stages on the dementia pathway	21
C. Middle stages on the dementia pathway	27
D. Late stages on the dementia pathway	31
Questionnaire: Your Comments on Proposed Strategies for Dementia Care and Support in Victoria 2005 and Beyond	37
Appendix 1 Victorian Dementia Working Group, Victorian Dementia Reference Group	45
Appendix 2 Major Forms of Dementia	46
Appendix 3 Pathway of Dementia	51
Appendix 4 Services in Victoria for people with dementia and their carers	53
Appendix 5 Graphs 1-8: Impact of dementia on the health and aged care systems	58
References	66



## **PURPOSE OF THIS CONSULTATION PAPER**

The dementia framework *Dementia Care and Support in Victoria 2000 and Beyond* has a life span to the end of 2004. It is timely to consider the achievements of the framework, and how to build on them into the future, given Victoria's changing demographics, and the research findings on dementia.

This consultation paper provides information about the past achievements in Victoria in dementia policy and practice, Victoria's changing demographics, the Victorian whole of government policy framework within which dementia directions for the state sit, opportunities for future action building on past achievements, and suggestions for dementia policy and practice from 2005 and beyond.

Given what has been achieved in dementia policy and practice in Victoria, recognizing changing demographics and findings of research over recent years, and building on past achievements, the Victorian Dementia Working Group and the Victorian Dementia Reference Group<sup>1</sup> auspiced by the Department of Human Services (DHS) have suggested several areas in which to extend dementia policy and practice. These areas are based on the concept of the "pathway of dementia". The process of dementia begins almost invisibly and insidiously, slowly affecting the person and those surrounding and interacting with them, and culminates in terminal decline of the person's central nervous system. Acknowledging these phases over time, suggested areas of focus to extend dementia policy and practice in Victoria are healthy and active living which may assist risk reduction and prevention of some dementias, and the early, middle and late stages on the pathway of dementia. The suggestions to enhance services and support include:

- Broad and generic strategies to further address identified issues.
- Documentation and promulgation of good practice.
- Research on, and identification and piloting of, innovative approaches for future service delivery.

While there is unlikely to be specific funding attached to the Dementia Framework for 2005 and Beyond, funding opportunities will be sought through the financial year. Opportunities for DHS cross program activity will also be sought in implementing dementia strategies. In addition DHS will continue seeking to enhance existing and build new partnerships with external stakeholders, to further dementia policy and practice in Victoria.

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1. Appendix 1 lists the members of the Victorian Dementia Working Group and the Victorian Dementia Reference Group.

## Your input sought

The purpose of this consultation paper is to stimulate your thoughts on building on achievements, for the dementia framework for 2005 and beyond. Questions seeking your views are posed throughout the section "Suggested Strategies 2005 and Beyond", and the questions are repeated with space for **your written comments** in the final section "Questionnaire: Your Comments on Proposed Strategies for Dementia Care and Support in Victoria 2005 and Beyond" (pages 37 – 44). You may not have views on all questions. You are asked to complete those questions you are able to, or most wish to comment on, and return the questionnaire by email, fax or mail to:

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Please return your questionnaire by **Friday 25 February 2005**.

## DEMENTIA

Before considering what achievements Victoria has made in dementia policy and practice, and how best to build on these, it may be useful to have some understanding of the term “dementia”.

Dementia is described as “a syndrome due to disease of the brain, usually of a chronic or progressive nature in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer’s disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.”<sup>2</sup>

The primary forms of dementia are: Alzheimer’s disease, Vascular Dementia, Lewy Body Disease, Fronto-temporal Dementia, Creutzfeldt-Jakob Disease (CJD), and Subcortical Dementia (including Parkinson’s Disease and Huntington’s Disease). Appendix 2 provides details of forms of dementia. The most common form of dementia is Alzheimer’s disease, followed by Vascular Dementia and mixed dementia, that is, features of both Alzheimer’s disease and Vascular Dementia.

Dementia can be described in terms of a series of stages, from initial and mild symptoms to a terminal decline of the central nervous system. These stages can be considered to be early, middle and late stages of the dementia pathway. Appendix 3 details stages of the pathway of dementia. There is variation in the symptoms that can occur during the course of dementia, and the way dementia affects each individual. Changes as dementia progresses are hard to pinpoint and may differ with different types of dementia. While stages of the pathway of dementia vary for individuals in duration, characteristics and significant crossings, individual autonomy continues to decline. Eventually, the effects of damage to the brain tissue are cumulative, disabling and terminal.

The stages of the pathway of dementia, accepted by practitioners and specialists in dementia as a framework for following the progress of dementia<sup>3</sup>, is a strategic approach that could be used for building on dementia policy and practice in Victoria. To build on achievements in Victoria, it is important to consider what those achievements are, and how the Victorian population is changing. These issues are addressed in the next two sections.

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2. World Health Organisation's *International Classification of Diseases - Clinical Descriptions and Diagnostic Guidelines*.

3. Victorian Government Department of Human Services (1997) *Dementia Care in Victoria: Building a Pathway to Excellence*, Aged, Community and Mental Health Division.

## **VICTORIA'S RECORD OF ACHIEVEMENT IN DEMENTIA POLICY AND PRACTICE**

In November 2000, building on previous developments in Victoria in dementia care and management, the then Minister for Housing and Aged Care, the Hon. Bronwyn Pike MP, announced the framework *Dementia – Care and Support in Victoria, 2000 and Beyond*. The framework aimed to:

- Improve the quality of care for people with dementia by strengthening education and training.
- Develop a service system more responsive to the needs of people with dementia, their carers and families.
- Improve access to services for people with dementia, their carers and families.
- Improve public awareness of dementia, and access to community education and information resources about dementia.
- Take a partnership approach to identifying and developing appropriate responses to the needs of people with dementia, their carers and families.

As a result of developments in Victoria over recent years, much has been achieved in dementia policy and practice on a wide range of fronts, and actions put into place to start addressing issues over the longer term. Achievements funded by government, peak community organisations, and service providers include the following.

### **Service system development**

Different people with dementia and their families and carers have various needs for services from pre-diagnosis to end stages of life. Generic community health services, continuing care services and services for senior Victorians continue to develop to meet the needs of Victorians. In addition, development of Victoria's service system to specifically meet the needs of people with dementia and their families and carers includes services for diagnosis and assessment of dementia available only in Victoria, services to support people with dementia living in their own homes, innovative services for care of people with behaviours of unmet need, and focusing on improving care for older people in health services. Initiatives include:

- Establishment of the Cognitive Dementia and Memory Service (CDAMS) clinics.
- Review of the CDAMS, and increased recurrent funding for the service.
- Growth of the Aged Persons Mental Health Program.
- Focus on people with dementia as a target group in Home and Community Care (HACC).
- Development of the Loddon Mallee Regional Dementia Management Strategy to improve services and service response to people with dementia and their families and carers, through a regional care pathway for dementia.
- The development and ongoing implementation of *Improving care for older people: a policy for Health Services*.

### **Support for people with dementia and their carers and families**

In addition to service development, there has been a growth in support services for people with dementia and their families and carers. People's individual needs for

support vary as dementia progresses, and a range of flexible, responsive and culturally sensitive support options have been developed to meet individual and changing needs, including of those people residing in non-government funded residential services, such as boarding houses and Supported Residential Services (SRS). These options range from support, counselling and the opportunity to network for people with dementia, to innovative and creative supports and respite for families and carers, and include:

- Establishment of the statewide Support and Links Counselling Service.
- Establishment of the Support for Carers of People with Dementia program, and growth funding of the program. The program aim is to purchase flexible support services to meet the individual and variable needs of families and carers of people with dementia: where there is a gap in the current service system; or where it is required and appropriate to top-up carer support services outside generic service systems; or in a crisis situation which cannot be met by other services.
- Recurrent funding for the Dementia Behavioural Support Program.
- Development of information by HACC for indigenous communities.
- Establishment of the Memory Lane Café which provides people with early dementia opportunities for accessing information and support in an empathic and understanding environment.
- Establishment and growth of the Support for Carers Program (SCP) which offers a range of flexible respite and support for older carers throughout Victoria, and includes specific funding for one Dementia Care Support Worker in each region to provide one on one support to carers of people with dementia.

### **Education and training**

Initiatives have been undertaken to train, educate and assist workers and providers in a range of settings on dementia care and management, and carer inclusiveness. These include direct and ongoing training, and the development of manuals or guidelines to assist staff and providers in dementia friendly and carer inclusive practice. Initiatives include:

- Education and training of community care staff including a focus on dementia in training of Home and Community Care (HACC) workers.
- Education and training of medical students in dementia awareness.
- Pilot projects in education and training in care and management of people with dementia in hospital settings<sup>4</sup>, with learnings to be disseminated statewide.
- Manuals and kits on transition to residential care, including carer inclusive practice by service providers.

### **Public awareness**

Initiatives to promote public awareness about dementia have increased, with Victoria's changing demographics, growing research on dementia, new treatments, and the focus on people living in their own homes with appropriate support. Dementia is increasingly spoken about in the media, with public figures and their families and carers indicating the impact of dementia on their lives. Peak bodies such as Alzheimer's Australia Vic

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4. These projects appear to reflect national directions for improving the care of older people across the hospital-aged care continuum. A national action plan on improving care outcomes for older people across this continuum is being released late in 2004.

(AAV) have developed a suite of information resources in community languages to suit different information needs, including for people with dementia and their families and carers, providers and staff, and the general public. Public awareness initiatives include:

- Information resources: Alzheimer's Australia's website, Help Sheets, etc.
- Ongoing financial support for a Policy Officer located in Alzheimer's Australia Vic (AAV).
- Ongoing financial and other support for Dementia Awareness Week.

Appendix 4 summarises services in Victoria for people with dementia and their carers.

There has been progress in meeting the needs of people with dementia and their families and carers<sup>5</sup>. The future sees changes in the demographic makeup of the Victorian population, and further opportunities for improvements in dementia policy and practice.

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5. There are also relevant past and current initiatives in *New Directions for Victoria's Mental Health Services, The Next Five Years* (2002), for example providing additional services for older people with mental illness.

## DEMENTIA AND THE CHANGING DEMOGRAPHICS OF VICTORIA

Various data sources:

- Identify existing demographics of Victorians relevant to cognitive impairment or dementia, including service users.
- Predict or estimate changes in future demographics and potential service users.

Data from different sources cannot usually be compared; for example, slightly different items may be measured over different time frames; a range of different assumptions is made in all future estimates and predictions. The Department of Human Services Aged Care Branch is working on developing a comprehensive demographic picture of dementia in Victoria, and its impact. In the meantime, the following data from a range of sources demonstrate various relevant factors and predictions regarding Victoria, dementia, and service users.

### Growth in Victoria's older population

In 2002, of Victoria's population of 4.8 million people, 1.4 million were aged 50 years and above (29%); 833,303 were aged 60 years and above (17%). By 2021, the proportion of Victorians over 60 years is expected to rise to 25%. Increased life expectancy means that many Victorians will be living into their 80s and 90s. Department of Sustainability and Environment *Victoria in Future 2004* population projections project a 21% growth in the Victorian population by the year 2021 (from 4.8 million in 2001 to 5.8 million people in 2021). The growth rate for the 70-84 years age group to the year 2021 will be substantially higher, expected to be about 66% (from 382,000 in 2001 to 632,000 people in 2021). The 85+ year age group will experience an even larger percentage increase, growing by 123% by 2021 (from 70,000 in 2001 to 156,000 people in 2021)<sup>6</sup>.

The aim of ageing and aged care policy and practice in Victoria is to maximise independence of older people to enhance their health and well being. The majority of seniors enjoy healthy, active and independent lives. Most live at home; a minority are in high or low level aged care facilities, or need public assistance for daily living. For those over 80 years of age, one-third require help with self-care activities, including people in residential care and at home.

### Demographics of dementia in Victoria

The changing demographics of the Victorian population are of importance for extending dementia policy and practice. Shorter term demographic trends and predictions for Victoria's population suggest that there are growing proportions and numbers of people with dementia, which will continue for at least the next two decades. In Victoria, it is estimated that in 2001 close to 41,000 people had dementia, with this figure estimated to increase to approximately 65,500 by 2021, a 61% increase.

This increase is not uniform across the state, because of differences in the projected population structures across the state. In metropolitan Melbourne, the number of people with dementia is forecast to increase from nearly 28,000 in 2001 to some 44,000 in 2021, an increase of 58%. The growth in actual numbers is forecast to be

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6. Source [www.dse.vic.gov.au/](http://www.dse.vic.gov.au/) See also Victorian Government Department of Human Services 2003. *Improving care for older people: a policy for Health Services.*

highest in the Southern Metropolitan Region, from 10,201 to 15,495 (a 52% increase), but the percentage growth is forecast to be highest in the western areas of Melbourne<sup>7</sup>, from 3,794 to 6,689 (a 76% increase).

In rural and regional Victoria, the number of people with dementia is forecast to increase from an estimated 13,000 approximately in 2001 to nearly 22,000 in 2021 (a 68% increase). The Gippsland Region is forecast to have both the highest numeric and the highest percentage growth in the number of people with dementia, with numbers forecast to rise from an estimated 2,353 to 4,481 (a 90% increase)<sup>8</sup>.

A more long term prediction is an increase in the number of Australians with dementia from 162,000 in 2002 to 500,000 in 2040, and 2.3% of the population by mid-century<sup>9</sup>. While more than 162,000 Australians have a diagnosis of dementia, there are currently perhaps as many again in the early stages of dementia<sup>10</sup>.

Whilst dementia is not exclusively experienced by older people<sup>11</sup>, the incidence of dementia increases with age. Prevalence is estimated to rise exponentially with age, doubling every 5.1 years of age after the age of 65 years. Among people aged 65 years and over, 6.5% are estimated to have dementia<sup>12</sup>. Of those aged 85 years and over, the estimate increases to 22-24% of people<sup>13</sup>.

The 1996 *Victorian Burden of Disease Study*<sup>14</sup> shows that in 1996 in Victoria, 88,978 years or disability adjusted life years (DALYs) were lost to dementia, and projects that by 2016 dementia will be the largest cause of ill health among women, and the fifth cause for men.

There are also various predictions of demographic change among carers, including carers of people with dementia<sup>15</sup>.

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7. Previously known as the Department of Human Services Western Metropolitan Region (WMR).

8. Alzheimer's Association Victoria 2001, *Information Sheet - The Prevalence of Dementia*.

9. Access Economics 2003. *The Dementia Epidemic: Economic Burden and Positive Solutions for Australia*.

10. Source [www.alzheimers.org.au](http://www.alzheimers.org.au) *Australian Dementia Statistics*.

11. In 2003, over 6,600 Australians under the age of 60 were living with dementia.

12. Alzheimer's Australia Vic, 2001.

13. Australian Institute of Health and Welfare (AIHW) 2004. *The impact of dementia on the health and aged care systems*.

14. Victorian Government Department of Human Services 1999. *Victorian Burden of Disease Study – Morbidity*. It was anticipated that the *2001 Estimates of Burden of Disease* report would be released before the end of 2004.

15. The Australian Institute of Health and Welfare (AIHW) in October 2003 released a report on *The future supply of informal care 2003 to 2013*. The AIHW concluded that "Shifts in carer responsibility that result from the changing availability of the group identified as primary carers will have implications for formal services and for the caring responsibility placed on others in informal networks. The effectiveness of these extended networks is dependent on the availability of relevant formal services and programs and on policies that facilitate broader community support". The National Centre for Social and Economic Modelling (NATSEM) was commissioned by Carers Victoria to report on *Who's going to care ? Informal care and an older population*. NATSEM somewhat similarly concluded in its report of June 2004 that "The demand for care by older Australians will continue to rise and only a declining share looks likely to be met by informal care. ... This points to the need for innovative policy options to provide the care that will be needed ... There may be a greater demand for institutional care due to an inadequate supply of primary carers. However, many older people are likely to continue to prefer options that support and allow them to stay in their own homes and this points to an increased need for services which provide supportive environments for people requiring community based support".

## Dementia and Community Care

There are several sources of data on the number of Victorians with dementia living in their own homes:

- A Home and Community Care (HACC) dependency pilot survey (2002).
- The ACAS Minimum Dataset (MDS).
- The Community Aged Care Packages (CACP)<sup>16</sup> Census (2002).
- The Extended Aged Care at Home (EACH)<sup>17</sup> Census (2002).

The HACC dependency pilot study surveyed almost 1,000 HACC clients; 5.2% were reported to have dementia. The rate for those under age 65 was less than 1%, but rose from 4% of those aged 65-74 years to 10% of those aged 85 or more.

An ACAS assessment is required for persons seeking CACP and EACH packages, but most of those who receive an ACAS assessment are living in the community at the time, and many are current HACC recipients. In 2003/04 some 26,000 Victorian HACC clients received an ACAS assessment, and their rate of diagnosed dementia was 25%. This HACC client subgroup is likely to be more dependent, but comprised 12% of all HACC clients.

The Victorian ACAS MDS showed that of all those living in the community at the time of assessment, 23.7% had dementia, a similar proportion to the subgroup assessed by ACAS and receiving HACC. The ACAS community rate rose from 18.8% at ages 65-74 to 24.2% for those aged 85 and over.

Of the 26,403 Australian CACP recipients in the CACP census, 4,646 (18%) were reported to be diagnosed with dementia by either a GP or ACAT. The dementia rate rose from 14% at ages 65-74 to 20% at ages 85 and over. It may be assumed that the Victorian and Australian dementia rates are similar. Those on EACH packages require more intensive community care; in the 2002 census of EACH recipients, 33% were estimated to have been diagnosed with dementia. Again the rate rose with age, from 15% of those aged 65-74 years up to 49% of those aged 85+.

These estimates cannot easily be summarised, because they are drawn from different points in the aged care system, and the diagnostic criteria may vary. The HACC program has by far the largest number of clients, and the dementia prevalence rates among HACC clients suggest some 10,000 persons with dementia. To them can be added perhaps 1250 on either CACP or EACH packages. The ACAS figures on the number of people with dementia are of a similar order.

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16. The CACPs census was undertaken by the AIHW. CACPs are Commonwealth Government funded, separate to HACC services, and provide an alternative to low-level residential aged care, delivering home-based care to frail older people or older people with a disability living in the community. CACPs assistance ranges from personal care and domestic assistance to delivered meals and transport. Anecdotally the data may underestimate the numbers of people with dementia; for example, care managers from one CACPs provider, asked about the number of people exhibiting symptoms of dementia, reported that in 2001/2002, some 40% of the program's client group had dementia, and in 2002/2003 some 44% of program clients had dementia. There were variations between catchment areas of 20% to 60%. This apparent underestimation could be the result of ACAS paperwork not being current at the time of the census. Future CACPs censuses can consider ways to capture accurate and current data on the cognitive status of clients.

17. AIHW 2004, *The impact of dementia on the health and aged care systems*. The EACH program, a Commonwealth Government program separate from HACC services, was established in 2001, and delivers to home based-care recipients nursing and personal care equivalent to high level residential care. When the EACH census occurred in May 2002, there were 288 Australians receiving EACH services. There were 84 EACH packages in Victoria as of 30 June 2003.

## **Dementia and Supported Residential Services (SRSs)**

Of approximately 7000 residents of SRSs, there are estimated to be almost 700 residents with a primary diagnosis of dementia, predominantly in the middle or late stages of dementia. Many hundreds of other SRS residents have multiple disabilities, including a complicating disability of dementia; these SRS residents would be predominantly in the early or middle stages of the dementia pathway<sup>18</sup>.

## **Dementia and residential aged care**

The then Commonwealth Department of Health and Family Services<sup>19</sup> provided estimates in 1997 of the level of cognitive impairment among residents of residential aged care facilities. Cognitive impairment was considered a more reliable indicator of cognitive deficits and subsequent care needs, than a reported diagnosis of dementia. The estimated levels of cognitive impairment in all Australian low level care facilities (previously known as "hostels") were:

- 34.9% mild,
- 16.6% moderate, and
- 2.9% severe,

and in all Australian high level care facilities (previously known as "nursing homes"), levels of cognitive impairment of residents were:

- 21.9% mild,
- 26.7% moderate, and
- 41.1% severe.

The report also estimated the proportion of residents rated with "challenging behaviour", or "behaviours of unmet need". Such behaviours may be challenging to staff in managing care needs, and often have a negative impact on other residents. The domains used to measure challenging behaviour were:

- Agitation.
- Wandering.
- Verbal disruption.
- Physical aggression.
- Inappropriate social behaviour.
- Resistance to care.
- Attention requirements, arising from the challenging behaviours.

For all Australian low level care facilities, the proportions of residents rated with challenging behaviour were:

- 75% no challenging behaviour,

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18. Source: Supported Residential Services Unit, Aged Care Branch, Rural & Regional Health & Aged Care Services, Department of Human Services, August 2004.

19. Commonwealth Department of Health and Family Services 1997, *Care Needs of People with Dementia and Challenging Behaviour Living in Residential Facilities, Resident Profile Survey Working Paper No 1*, Aged and Community Care Service Development and Evaluation Reports.

- 18.5% mild level of challenging behaviour,
- 4.9% moderate level, and
- 1.3% severe level,

and for all Australian high level care facilities, the proportions were:

- 32% no challenging behaviour,
- 32.2% mild level of challenging behaviour,
- 21.8% moderate level, and
- 14% severe level.

### **Impacts of changing demographics on health and aged care costs**

For 2000/01 it is estimated that expenditures in Australia for dementia by the health and aged care systems were over \$2.5 billion (excluding several state specific aged care services, both mainstream, and targeting people with dementia and their families and carers, such as the Victorian Cognitive Dementia and Memory Service Clinics). Some 84% of this expenditure was for residential aged care (\$2.1 billion). Excluding health expenditure in residential aged care, expenditure for dementia by the health system was \$307 million in 2000/01. Over half of this expenditure was by hospitals (\$160 million) and about 9% was for pharmaceuticals (\$27 million)<sup>20</sup>.

More long term predictions include an estimated \$6.6 billion cost to Australia of dementia in 2002, and an increase in dementia costs from almost 1% of GDP in 2002 to more than 3% by 2050<sup>21</sup>.

Appendix 5 presents graphs developed from data in the 2004 Australian Institute of Health and Welfare report, *The impact of dementia on the health and aged care system*.

Given achievements to date in dementia policy and practice in Victoria, and existing and predicted demographic data about dementia, opportunities can be identified for possible future action and strategies proposed for dementia policy and practice from 2005 and beyond. The remainder of this document identifies opportunities for action, and proposes strategies for consideration.

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20. AIHW 2004, *The impact of dementia on the health and aged care systems*.

21. Access Economics 2003. *The Dementia Epidemic: Economic Burden and Positive Solutions for Australia*.

## **OPPORTUNITIES FOR FUTURE ACTION IN DEMENTIA POLICY AND PRACTICE**

Both State and national events can influence opportunities for future action in dementia policy and practice in Victoria.

### **AT THE STATE LEVEL**

Victoria's whole of Government policy framework *Growing Victoria Together* (GVT) identifies directions for Victoria's way forward, including:

- Maintaining a strong public health system.
- Strengthening rural, regional and urban communities.
- Linking Victoria to promote social cohesion and growth.
- Reconciliation between indigenous and non-indigenous Victorians.
- Planning for the needs of our changing population at all stages of life.

A key strategic issue identified in GVT for Victoria is "High quality, accessible health and community services". GVT indicates that there will be continued investment to improve local access to essential health, aged care and community services, particularly in rural and regional communities. The challenges include "increased demand for services and an ageing population". A priority action for this strategic issue is to "Support older people to live active lives in the community".

The dementia framework from 2005 and beyond, building on past achievements to better meet the needs of Victorians with dementia, and their families and carers, can reflect the directions and strategic issues of GVT, through seeking to:

- Promote and protect the rights of older people with dementia.
- Support older people with dementia to live active and independent lives in their communities where possible and desired.
- Facilitate high quality accessible health and aged care services to support people with dementia, and their families and carers.
- Encourage creativity and innovation in flexible service delivery. This may involve the reconfiguring of service delivery models, and developing and refining service design.
- Focus on social connectedness, diversity and equity, including being responsive to the diverse needs and preferences of individuals in delivery of dementia services.

Considering achievements to date on dementia policy and practice in Victoria, Victoria's changing demographics, and whole of government policy directions, opportunities for further work in dementia include:

### **Support older people to live active and independent lives in their communities**

- Increase public health awareness of the effect of lifestyle choices regarding coronary health, smoking, diet, etc, on delaying the onset of or preventing certain dementias. There is low awareness of the causes of, and ability to delay onset of or prevent, certain dementias.

- Facilitate generic community education about people with dementia living in the community and accessing services, and the importance of early diagnosis of dementia.
- Support the development of training materials and programs to facilitate GPs recognising possible dementia and making appropriate referrals (or in diagnosis of dementia)<sup>22</sup>, and in supporting people with dementia and their families and carers.

#### **Facilitate high quality health and aged care services to support people with dementia, and their families and carers**

- Identify useful and appropriate diagnostic and screening tools which can be used by appropriate health professionals.
- Incorporate dementia care and management into hospital care practice<sup>23</sup>.
- Increase the awareness of service providers in dementia care issues to improve service co-ordination and reduce service system complexities.
- Refine strategies on the care and management of people with dementia and with behaviours of unmet need (described by health professionals as challenging behaviours, or behavioural and psychological signs and symptoms of dementia - BPSDD), which may be challenging to staff and other residents in residential care.

#### **Encourage creativity and innovation in flexible service delivery**

- Provide more flexible innovative respite and care models in the community care, Supported Residential Services (SRS), and residential care systems.
- Promote evidence based programs, and continuous improvement based on practice.

#### **Focus on social connectedness, diversity and equity**

- Further develop strategies in the care and management of dementia in indigenous communities, for culturally and linguistically diverse communities, and for other marginalised people such as people who are homeless.

#### **AT THE NATIONAL LEVEL**

In July 2004 the Commonwealth Government announced \$4.6 million over five years for research into dementia; the research will focus on early detection and prevention of neurocognitive disorders, including dementia and depression in older people, to help GPs recognise these conditions, and manage them more effectively.

Prior to the 2004 election, the Coalition released its policy on *Dementia – a National Health Priority*. The policy is to provide \$200 million over four years:

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22. The National Aged Care Alliance has called for GPs to be provided with education and support to implement models of care that include early diagnosis. The AIHW (2004) estimates that in 2001/02, about 5% of GP adult patients (aged 18 years and over) had either diagnosed or suspected dementia, with these patients more likely to be 75 and over, and female (AIHW 2004, *The impact of dementia on the health and aged care systems*).

23. Identified as a policy direction in *Improving care for older people: a policy for Health Services*, Department of Human Services. The Department of Human Services has recently funded four projects in the education and training of all staff in the hospital setting in the care and management of patients with dementia. An evaluation report on the four projects is currently being completed.

- \$52.2 million to make dementia a national health priority, providing a focus for monitoring, reporting on and developing strategies to improve health outcomes for people living with dementia.
- \$127.7 million for an additional 2,000 Extended Aged Care in the Home (EACH) packages.
- \$20.1 million to expand the Carer Education and Workforce Training (CEWT) project, to provide dementia-specific training for up to 8,000 community care staff and residential care workers, and up to 6,000 extra carers and community workers such as police and transport staff.

The Australian Health Ministers Conference (AHMC) in 2004 requested that all the states and territories consider areas for possible action in dementia at a national level, and propose a national consultation process. As a result, a paper compiled by the states and territories on a *National Framework for Action on Dementia* has been put to the Australian Health Ministers Advisory Council (AHMAC), in preparation for the AHMC meeting scheduled for January 2005<sup>24</sup>.

Within these State and national environments, the following section suggests strategies for future action to address opportunities for change outlined above.

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24. Work at a national level is also being done by other organisations such as specific interest bodies. For example, the Council of Older Australians Working Group (COAWG) has commissioned a project on best practice approaches to prevent functional decline in the older person across the acute, sub-acute and residential aged care sectors, and is to commission a new project on the Delirium Care Pathway.

## **OVERVIEW - DEMENTIA POLICY AND PRACTICE 2005 AND BEYOND**

People with dementia are both inside and outside the service system, so support and care emanates from within communities and from service providers. Responsibility for action around dementia rests with a range of organisations, including State Government, peak bodies, advocacy groups, researchers, service providers, local governments, and the Commonwealth Government. It is important that partnerships continue to build, and that efforts are further coordinated across all these areas.

Given what has been achieved in dementia policy and practice in Victoria, acknowledging the changing demographics, and recognizing the opportunities for action identified above, this Consultation Paper suggests strategies for dementia policy and practice. While the following suggestions for building on past achievements are made around the pathway of dementia, the pathway is a process tool to identify needs and service gaps. The experiences of people with dementia and their families and carers are within their communities. Furthermore, it is considered that if the full continuum of services meets the needs of people with dementia and their families and carers, this will reflect the development of a quality service generally<sup>25</sup>.

Stages on the pathway of dementia vary for individuals in duration, characteristics and significant crossings from stage to stage. There are both common themes along the dementia pathway, and individual needs of people with dementia, and their families and carers.

### **Common themes and individual needs along the pathway of dementia**

Common themes, presenting to varying degrees and from time to time along the pathway of dementia, include the need for:

- Support for people with dementia and their families and carers, including flexible respite.
- Information and resource materials.
- Participation of people with dementia and their families and carers in decisions about diagnosis, treatment and care.
- Training and education for all people involved in the care of people with dementia, including families, volunteers and service providers.
- Research on risk reduction, prevention, treatment and care practices.
- Community education and responsiveness, including community awareness and de-stigmatisation, community support and social connectedness<sup>26</sup>.

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25. A similar concept has been argued for developing quality care for people with confusional states in hospitals. See Inoye SK, American Journal of Medicine, May 1999, 106, 565-573.

26. Social connectedness is said to be a stronger predictor of perceived quality of life in a community than the community's income or educational level. Personal happiness is similarly a stronger predictor of perceived quality of life. These predictors have been increasingly recognised in the work on community building and social capital (*The Social Capital Community Benchmark Survey, USA, 2000, Executive Summary* by The Saguaro Seminar: Civic Engagement in America, John F. Kennedy School of Government, Harvard University). The dementia framework for 2005 and beyond aims to promote people with dementia and their carers remaining active and participating members of their communities and encouraging efforts to facilitate this, seeking support from the Department of Victorian Communities and the Primary Care Partnerships.

- Appropriate care and management in hospitals of older people with complex needs and of people with cognitive impairment<sup>27</sup>, including reducing the use of physical or chemical patient restraints, which increase the risk of adverse events<sup>28</sup>.
- System interfaces/ design – entry to a continuum of care system in the early stages offers an opportunity to build confidence in the system, and reduce at the middle and late stages crisis management and premature admission to residential care.
- Removing restrictions in the service system which can work against innovative practices.
- Protection of rights and interests.
- Strategies for preventing elder abuse.
- Preventing behaviours of unmet need (described by health professionals as challenging behaviours, or behavioural and psychological signs and symptoms of dementia - BPSSD).

While these issues or themes can occur along the pathway of dementia to a greater or lesser extent, specific strategies are suggested below to address them at various stages of the pathway.

Some people have special needs to be addressed, with particular strategies designed to support them and their families and carers. These people, who may find the service system not especially user friendly, include:

- People from culturally and linguistically diverse (CALD) backgrounds<sup>29</sup>.
- Indigenous communities.
- People who are homeless<sup>30</sup>.
- Other special needs groups such as people with Down syndrome and dementia; people with younger onset dementia<sup>31</sup>, etc.

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27. AIHW (2004) estimates that dementia impacts more on hospital services than on general practice. In 2001/02, 1.2% of hospital separations (79,000 separations Australia-wide) involved people with a principal or additional diagnosis of dementia. People with dementia tend to stay longer than others in hospital; in 2001/02, excluding same-day separations, those with a principal diagnosis of dementia stayed in hospital for an average 32.6 days, compared with 6.5 days average stay for all patients in Australian hospitals (AIHW 2004, *The impact of dementia on the health and aged care systems*). Victorian Admitted Episodes Database (VAED) indicates that from 1 July 2003–30 April 2004, there were 14,964 patients over 40 years of age admitted to public and private hospitals with a dementia diagnosis, as a principal or an additional diagnosis.

28. DHS *Improving Care for Older People*, p. 9.

29. For example people from CALD backgrounds may be slower to receive diagnosis, and access care and support systems. Language and cultural specificity are critical for the delivery of some services; for example in a multicultural adult day care program incorporating Chinese, Italian and Greek people, attendees may find it difficult to socialise and participate in activities if they do not speak a common language or share a cultural identity. Another issue is the apparent propensity for CALD people to revert to their first language as dementia progresses, and appropriate service system responses (see Runci, 2004). System responses need careful consideration. For example, interpreters who do not understand dementia, language loss and the regional and cultural identity of an individual may not interpret well regarding a CALD person with dementia. Some aged care residential facilities cater for specific cultural and linguistic needs; there is a challenge for other mainstream organisations to develop ethno-specific services without increasing service delivery cost.

30. Issues for homeless people are identified in the *VAHEC Homeless Taskforce Community Care Issues Paper 2002*.

31. In 2003, some 277 people aged less than 50 years received residential aged care services in Victoria. In 2004, DHS has nominated as a Strategic Project *Developing Appropriate Options for Younger People with Disabilities Eligible for Residential Aged Care Services*, with proposed completion of June 2005. The target group includes younger people with disabilities aged less than 65 years, particularly focusing on those aged 50 years and less. Project objectives include developing more appropriate and sustainable long-term

Strategies building on past achievements are suggested below for:

- A. Preventing and reducing the risks of dementia - healthy and active living.
- B. Early stages on the dementia pathway<sup>32</sup>.
- C. Middle stages on the dementia pathway<sup>33</sup>.
- D. Late stages on the dementia pathway<sup>34</sup>.

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accommodation and support options for younger people with disabilities to: improve service responses to those requiring the level of care provided in residential aged care services; create opportunities for those seeking to move from residential aged care to more appropriate community options; and prevent inappropriate admissions.

32. Research suggests that Victoria will experience a growing demand for early expert diagnosis, advice and support to and from individuals, families, carers and health providers – DHS *Review of the Cognitive, Dementia and Memory Service Clinics*, LaTrobe University 2003. Through early diagnosis and intervention, people are able to live meaningful, more productive lives for longer periods, health and coping skills of carers can be improved, and institutionalisation of people with dementia can be delayed – Access Economics 2003 *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia*.

33. Non-specialists in dementia may identify the middle stages of the dementia pathway as early stages. Primary Care Partnerships (PCPs) may provide opportunities for health professionals to reach understanding about defining the stages.

34. Work by Brodaty and others suggests that in the late stages of dementia, training or intervention support for carers has positive impacts on both the carers and care recipients; for example, training of carers of people with dementia has been associated with: increased patient survival, and fewer deaths, at home; delayed placement of a person with dementia in a residential aged care facility; and decreased psychological morbidity in carers. Training or intervention appears to improve carers' knowledge, decrease family burden, and improve coping skills.

## **SUGGESTED STRATEGIES 2005 AND BEYOND**

Broad and generic strategies to address identified issues are suggested. They include documentation and promulgation of good practice, and research on, and identification and piloting of, innovative approaches for future service delivery.

### **A. Preventing and reducing the risks of dementia - healthy and active living**

#### **Introduction**

There is increasing evidence on how to reduce the risk of dementia, and it is expected that this evidence base will strengthen in the next few years<sup>35</sup>. In the future, as more is learned about dementia, minimising or reducing its debilitating effects might be achieved in various ways:

- Prevention per se, that is, a person might never get dementia.
- Delay in disease onset, so that a person may have fewer years living with dementia after diagnosis, before their symptoms progress significantly.
- If a person is diagnosed very early, treatments may delay further progression of the condition, so that the person can remain living independently in their own home.

The implications of having fewer people with dementia are highly significant, from quality of life and cost perspectives. A two year delay in onset is predicted to reduce the prevalence (that is, numbers) of people with dementia by 20% over 50 years and a five year delay in onset is predicted to produce a 50% reduction over 50 years<sup>36</sup>. Such reductions in the onset of dementia would have a major effect on quality of life of many people, and their families and potential carers. Any reduction in dementia is positive. Raising community awareness about risk reduction and findings about prevention enables people to better prepare for new risk reduction and prevention strategies and/or treatments as these emerge.

#### **Issues**

1. Dementia is not widely recognized as a major public health issue on which positive action can be taken to reduce its impact in the coming decades.
2. People are unclear about risk reduction measures.
3. Prevention strategies need to be seen in a cultural context, and be culturally sensitive.
4. Many people are poorly prepared for advanced planning, for example enduring powers of attorney, which are helpful if a person develops dementia (or other significant conditions)<sup>37</sup>.

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35. The increased risk of later life dementia in those with mid-life hypertension as identified in the Honolulu Study is one example. The potential for dementia prevention was recently reviewed. See Lautenschlager N T et al 2003, *International Psychogeriatrics*. Vol 15, No 2 p 111.

36. See Brookmeyer, Gray, and Kawas 1998.

37. Low take-up rates of enduring powers of attorney may be due to the complexities involved, including the fact that there are three separate documents for enduring powers of attorney dealing with: financial matters; medical matters; and guardianship.

## Desired Outcome

There is a reduction in expected prevalence of dementia in the community, due to a delay in or prevention of onset of dementia.

**Prompt:**

What are **your** two most important suggested strategies to meet this desired outcome, given the above issues?

1. ....
2. ....

## Possible Strategies

### *Research*

1. Support research into risk reduction and prevention of dementia.

### *Promoting positive ageing, and social connectedness*

2. Encourage the Commonwealth Government to promote a national approach to risk reduction and prevention of dementia, especially in terms of public health<sup>38</sup>.
3. Support and facilitate community awareness raising activities on risk reduction for dementia by various means including by partnering with other relevant organisations such as the Cancer Council Victoria, Heart Foundation, the Stroke Association of Victoria Inc, VicHealth and ethno-specific organisations. Life long lifestyle messages - around 'healthy body and healthy heart make for a healthy mind' - include:
  - a) Quitting smoking.
  - b) Reducing high blood pressure.
  - c) Reducing high cholesterol.
  - d) Maintaining mental and physical activity.
  - e) Having a healthy diet.
  - f) Maintaining an appropriate weight.
4. Seek to continue work on healthy and active living for all, and positive ageing strategies, with the:
  - a) Ministerial Advisory Council of Senior Victorians.
  - b) Office of Senior Victorians (OSV).
  - c) Seniors Information Victoria, Council on the Ageing (COTA).
  - d) Alzheimer's Australia Vic (AAV).
  - e) Carers Victoria.

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38. As indicated previously, prior to the 2004 national election, the Coalition released a policy on *Dementia – a National Health Priority*. The policy is to provide \$200 million over four years, including \$52.2 million to make dementia a national health priority.

- f) DHS program areas, such as HACC, ACAS, Continuing Care, Mental Health, Primary and Community Health, Public Health.
  - g) Primary Care Partnerships (PCPs).
5. Explore the opportunities for regional initiatives on dementia and healthy ageing.
  6. Use appropriate seniors web sites such as <http://www.seniors.vic.gov.au/> to promote regional and statewide initiatives around community education.
  7. Seek to encourage options for travel and mobility such as community transport.

### *Early life planning*

8. Promote awareness about developing Living Wills.
9. Support the work of the Public Advocate to increase awareness in the community about the benefits of early life planning for the future, taking out powers of attorney, and organising advanced care directives<sup>39</sup>.

**Question A - Preventing and reducing the risks of dementia - healthy and active living**

Please answer these questions on pp. 37-39.

- i) What comments do you have on the above possible strategies, and how to implement them?
- ii) What other strategies could be added?
- iii) What examples of good practice can you identify of awareness raising activities about prevention and risk reduction of dementia?
- iv) What strategies can you suggest to ensure that the interests of special needs groups are met? (Special needs groups include Indigenous people, people of cultural and linguistic diversity, homeless people, people with Down syndrome, and people with younger onset dementia).
- v) For your organisation or sector to address the issues raised, what:
  - do you currently do?
  - could you do?

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39. There may be opportunities to promote law reform, to simplify and unify the documentation required for people wishing to arrange the three enduring powers of attorney for: financial matters; medical matters; and guardianship.

## B. Early stages on the dementia pathway

### Introduction

Growing knowledge of the various dementias increasingly enables their accurate diagnoses, together with specific medical treatments, other types of support, and education. Accurate diagnoses leading to appropriate treatment and care result in better outcomes for people with dementia and their carers, and more functional family relationships.

Research by Alzheimer's Australia has shown that while dementia and Alzheimer's disease are very well recognized and broadly understood by the community, people are generally uncertain about acting on their concerns, the availability and benefits of medications, and support services. Some people fear a diagnosis of dementia, and what this may mean for their future. It is a challenge for service providers to acknowledge such feelings, and using a positive approach assist people through them.

In the early stages on the dementia pathway, it is important to be able to accurately differentiate between early dementia, and other conditions that may be taken for dementia. For example, changes in individuals can occur through "normal" ageing<sup>40</sup>, some people may develop a Mild Cognitive Impairment (MCI)<sup>41</sup>, others may have delirium or depression<sup>42</sup>, and some may have dementia.

For people diagnosed with dementia in the early stages of the dementia pathway, differentiating the dementia can be important, as it may have implications for management and treatment (including the need to exclude reversible causes)<sup>43</sup>.

The ability to predict the rate of progression is important. As the first signs of dementia develop, a person may be able to participate in completing wills, designating enduring powers of attorney dealing with financial matters, medical matters, and guardianship, and completing unresolved issues and other business, before cognitive incompetence occurs. It can be a crucial time for family members to prepare and plan for the future. The health professional can assist with early planning, and education, and provide appropriate care and referral. Strategies can be provided to assist with management, behavioural function, and carer support.

Most people with early stages of dementia continue to live active and productive lives in their own homes. People in the early stages on the dementia pathway who may have no other accommodation can also in most circumstances have their accommodation needs met in Supported Residential Services (SRS) accommodation<sup>44</sup>.

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40. "Normal" ageing processes affect individuals differently, with individual responses to ageing. Several ageing processes, perhaps operating together, may result in cognitive changes (O'Brien et al, 2000: 15). In "normal" ageing, some abilities may improve or remain stable over time (for example, use of vocabulary) but other abilities may decline because of changes in the central and peripheral nervous system (for example, speed tasks). Many people live healthy and active lives through ageing.

41. MCI is a clinical diagnosis given if a person is impaired in more than one cognitive domain. While MCI is most commonly considered to affect memory, it can result in isolated impairment in language and executive function (for example, decision making).

42. Appendix 2 provides details of depression and delirium, which can mimic dementia.

43. Appendix 2 lists forms of dementia and their features.

44. As with all residential facilities and accommodation: SRSs vary in quality; suit different individual needs and preferences; and do not suit all people eligible for them. Some SRSs charge fees that are less than pension rates plus rent assistance. SRS may be a home of choice before an onset of dementia, or significant deterioration in decision-making capacity. Where SRS accommodation is shown to be inappropriate for an individual resident, alternative arrangements are made by the SRS proprietor and/ or DHS.

Appendix 3 provides more detail of this stage on the pathway of dementia.

### Issues

1. Dementia is still stigmatized, and people may fear a diagnosis of dementia and what it may mean for their future. There may be reluctance to recognize the benefits of early diagnosis and early support and information, for people with dementia and for their families and carers. These issues are even more marked in culturally and linguistically diverse communities.
2. GPs and other primary health care providers are not all able to recognize possible dementia, and therefore facilitate early diagnosis, appropriate early planning, and support for people with dementia and their families and carers.
3. Other service providers are not all alert to the possibility of cognitive decline, and so do not provide appropriate support and referrals.
4. Commonwealth Government policies, programs, and initiatives such as the Community Care Review, ACAS initiatives in the Commonwealth Government budget, etc, impact on service delivery, for example on levels of funding, program guidelines, and service system development.

### Desired Outcome

People with dementia and their carers begin early access to a continuum of quality care, including treatment, and maximise active community involvement.

**Prompt:**

What are **your** two most important suggested strategies to meet this desired outcome, given the above issues?

1.  
.....
2.  
.....

### Possible Strategies

#### *Promoting positive ageing, and social connectedness*

1. Seek to continue work on healthy and active living, positive ageing strategies, and information about dementia, with the:
  - a) Ministerial Advisory Council of Senior Victorians.
  - b) Office of Senior Victorians (OSV).
  - c) Seniors Information Victoria, Council on the Ageing (COTA).
  - d) Alzheimer’s Australia Vic (AAV).
  - e) Carers Victoria.

- f) DHS program areas, such as HACC, ACAS, Continuing Care, Mental Health, Primary and Community Health, Public Health.
  - g) Primary Care Partnerships (PCPs).
2. Explore the opportunities for regional initiatives on dementia and healthy ageing.
  3. Use appropriate seniors web sites such as <http://www.seniors.vic.gov.au/> to promote regional and statewide initiatives around community education on dementia and healthy ageing.
  4. Promote ways to maintain social connectedness within communities, for people with dementia and their families and carers.

### ***Life planning***

5. Promote awareness about developing Living Wills.
6. Support the work of the Public Advocate to increase awareness in the community about the benefits of planning for the future, taking out powers of attorney, and organising advanced care directives.

### ***Education and information***

7. Promote community awareness raising and education about dementia, for example regarding symptoms, what to do about them, and availability of information. Often neighbours and friends are the first to notice signs of cognitive impairment, and assist people to access services.
8. Promote the availability of quality, current information on dementia, treatments, support and services<sup>45</sup>, on the web, in print and in other formats suitable for community groups including people from culturally and linguistically diverse backgrounds (CALD).
9. Promote general understanding and information on dementia to increase awareness of customer service and hospitality industries such as banking, shopping, hotel/boarding house accommodation, and other front line staff.

### ***Service development and enhancement***

9. Promote and extend the access to Cognitive Dementia and Memory Service (CDAMS) services<sup>46</sup>.

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45. For example, the dental health booklet *Oral Health for Older People. A Practical Guide for Aged Care Services*, Department of Human Services 2002.

46. CDAMS clinics were set up by the Victorian Government to provide an early diagnosis of cognitive and or memory deficits and treatment services for dementia. The 14 CDAMS clinics are an 'accessible, multidisciplinary, specialist service providing early diagnosis, advice, support and referral for people with cognitive difficulties'. The CDAMS clinic functions as a multidisciplinary team and consists of specialist professionals. Each person referred to CDAMS receives assessments, interventions and a feedback family meeting. The diagnostic formulation and management plan are discussed at a case conference and with the client and their family members. Three aspects of a CDAMS service are considered critical: providing diagnostic assistance and immediate help to people with cognitive impairment and/or dementia; supporting their families and carers; and providing education. CDAMS is considered to reduce stress and anxiety, give an opportunity for control to people with dementia and their families and carers, and maximize preventive treatment effects for those with dementia. They aim to assist carers and families to conceptualise and articulate their concerns, and access education and other supports.

10. Promote and where appropriate enhance GP services, for example:

- a) Facilitate appropriate training and support to GPs in: early identification of possible memory and thinking issues/ cognitive impairment, and more developed cases of dementia; making appropriate referrals; and facilitating appropriate early planning and support for people with dementia and their families and carers<sup>47</sup>. There may be opportunities for CDAMS to train GPs in screening for dementia, or in some cases distribution of CDAMS clinical diagnosis workloads to diagnose dementia<sup>48</sup>. Seek to further engage the Commonwealth Government in assisting GPs with diagnosis, management and care of people with dementia<sup>49</sup>.
- b) Out-post community practitioners, for example AAV counsellors, Royal District Nursing Service (RDNS) staff, ACAS workers, or other community care workers with expertise in dementia, to support GPs in their work with people with dementia. Facilitate the use of Practice Nurses in GPs, or a case manager in GPs – for example the Hospital Admission Risk Program (HARP) model<sup>50</sup>, which boosts community capacity to keep people out of hospital, Enhanced Primary Care (EPC) and pharmaceutical reviews. Existing models utilising practice nurses could be extended to other disciplines with expertise in dementia, to provide holistic care through general practices.

These strategies are consistent with directions in Victoria's Community Health Services<sup>51</sup>.

11. Promote and where appropriate extend other services such as ACAS – seek to increase ACAS skill and capacity to undertake assessments where there are

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47. Recommendation 7 of the 2003 CDAMS review refers to the need for collaborative relationships between CDAMS and primary and community care providers, including general practice, to improve continuity and quality of care, for example by examining models of shared care for those with dementia, and joint ventures in dementia education. Recommendation 9 suggests that GPs undertake ongoing review and monitoring, within a formal multidisciplinary care plan, of people with dementia.

48. The CDAMS review suggests that GPs diagnosing and managing non-complex cases of dementia would ease demands on CDAMS. The Austin Health CDAMS is trialling a rapid assessment triage system which includes: MMSE, carer assessment, physician structured interview, and CogHealth Memory Monitoring System testing. It has been suggested that the triage system, which appears to be working well in the trial, could be used in GP surgeries, enabling early dementia screening.

49. As previously indicated, in July 2004 the Commonwealth Government announced \$4.6 million over five years for research into dementia; the research will focus on early detection and prevention of neurocognitive disorders, including dementia and depression in older people, to help GPs recognise these conditions, and manage them more effectively.

50. To enhance existing infrastructure rather than establishing new services, the principles and learnings of HARP can be applied to dementia services. HARP projects have demonstrated methods of increasing the capacity of community services to reduce the demand on more costly forms of care, such as residential, acute and sub-acute care for older people at risk of hospital admission. These models could equally be applied to supporting people with dementia.

51. The clientele of Community Health Services (CHSs) has a concentration of people on lower incomes, older people and children. More than 80% are Health Care Card holders and most have, or are at risk of, chronic and complex conditions. Growing evidence points to the central role of primary health care in improving health and wellbeing, and reducing demand for more specialised, acute and sub-acute services. General directions for CHSs include: a) diverting patients from, or providing substitute services for, acute and sub-acute services; b) increasing access to affordable and accessible GPs in CHSs, and building strong functional relationships between CHSs and private GPs to improve health outcomes for local communities; c) tackling inequalities and promoting social connectedness; and d) strengthening partnerships especially with hospitals, GPs and local government, to provide continuity of care to people with complex and chronic conditions and disabilities, so they can live independently in their own communities. The DHS *Community Health Services - creating a healthier Victoria* policy was released in 2004.

memory or orientation issues, and to provide advice to service providers as part of care planning and service co-ordination, managing behaviours, etc. ACAS would require regular training and information on the latest findings on dementia care and management<sup>52</sup>.

### *Screening tools*

12. Identify validated screening tools for dementia and minimum standards for use by other health services, and identify and facilitate resourcing to use the tools.

The MMSE (Folstein et al, 1975) which has been standardized (Molloy et al, 1991) and shortened, is a commonly administered tool in ascertaining cognitive impairment, often used as a prerequisite to further testing and investigations. Without the assistance of screening instruments clinicians may commonly miss dementia in routine practice<sup>53</sup>. Other screening instruments include the clock-drawing test, and the Alzheimer's disease Assessment Scale<sup>54</sup>. Some tools have a dual role in incorporating cognitive screening instruments and diagnostic schedules<sup>55</sup>. Other tools focus on information from families and carers<sup>56</sup>.

13. Promote the development and validation of culturally sensitive screening tools for dementia and minimum standards for use<sup>57</sup>, for example the RUDAS developed for those of CALD backgrounds<sup>58</sup>. In the application of culturally sensitive tools, include the use of appropriately skilled and experienced bilingual bicultural people and bilingual personal carers, where appropriate.

### *Support for people with dementia and their carers*

14. Promote the provision of early support to the person with dementia.

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52. The Commonwealth Government in August 2004 released its review of community care, *A New Strategy for Community Care – The Way Forward*. Actions 4.4 and 4.5 are aimed at streamlining contractual arrangements for delivery of dementia services, and merging the Dementia Support for Assessment Program with the Aged Care Assessment Program. This appears to be administrative streamlining, rather than service streamlining and co-ordination.

53. See Williamson et al., 1964; Mant et al., 1988; cited by Flicker in O'Brien et al.: 82, 2000.

54. The latter is known as ADAS-cog. See Rosen et al., 1984.

55. For example, the Cambridge Diagnostic Examination for the Elderly (CAMDEX) (Roth et al., 1986; in O'Brien et al., 2000), and the Geriatric Depression Scale (Yesavage; 1988).

56. The Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) (Jorm and Korten, 1988) is a structured screening test administered to informants to detect cognitive impairment. In addition the Dysfunctional Behaviour Rating Instrument (DBRI) (Malloy; 1991) has been developed to screen and measure behavioural manifestations of both client and informant.

57. There is no validated tool to assess cognition in older indigenous Australians. Recent research by Dr Dina LoGiudice et al on 70 indigenous people over 45 years old, living in the Kimberley area of Western Australia, was presented at the Australian Society for Geriatric Medicine in Fremantle in 2004, and at the ACAS Victorian Dementia Training Day, 18 August 2004. Issues influencing diagnosis among indigenous people include: a different concept of dementia; culturally accepted physical, social and psychological reasons for change in cognition; epidemiological/ cross-cultural influences; and history. Factors to be considered in diagnostic tools include: tribal diversity; many spoken languages; no written language; limited schooling; concepts of number, time, space, and family; name and age; depression and psychosis; informant history; and propensity to respond "appropriately" to others. LoGiudice et al have developed the Kimberley Indigenous Cognitive Assessment (KICA) tool.

58. The Rowland Universal Dementia Assessment Scale (RUDAS) was developed as a simple method for detecting dementia that is valid across cultures, portable and easily administered by primary health care practitioners. See Storey et al.

15. Promote the provision of support to their families and carers, through counselling and other support options, including peer and self help support. Teenagers with a parent or grandparent with dementia may especially benefit from counselling.
16. Promote responsive and timely support for people with dementia and their families and carers, as needs begin to change with the progression of dementia, and the need for other support increases, for example HACC services, and respite services.
17. Promote quality of life of people with dementia, and their families and carers, with socialising and maintenance of community living, including supportive programs for couples. Identify effectiveness of existing services such as HACC Planned Activity Groups High (PAGS High), and facilitate appropriate and timely services.
18. Continue to promote appropriate policy and practice in HACC so that HACC clients with cognitive impairment can access appropriate services and assistance<sup>59</sup>. Seek opportunities to enhance support to HACC staff, for example through continued provision of training opportunities, advice and written resources.
19. Promote awareness about changing driving capacity, and seek to encourage options for travel and mobility such as community transport.

#### *Respite and residential accommodation*

20. Assist service providers to provide early responsive respite that meets needs, for example providing low key responsive respite early, rather than in crisis situations alone, and providing where appropriate culture and language specific respite.
21. Promote appropriate policy and practice in Supported Residential Services (SRSs) for residents with a diagnosis of dementia and their families, and other health care providers. Seek opportunities to provide support to SRS operators, for example through the provision of training opportunities, advice and written resources.
22. Continue approaches to the Commonwealth Government regarding subsidy rates and low admission rates of people with dementia who are recommended for residential care. Seek opportunities to provide support to residential care facilities, for example through the provision of training opportunities, advice and written resources, to encourage a better understanding of caring for people with dementia.

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59. In an address to the Victorian Dementia Reference Group in November 2004, the Public Advocate referred to the need for policies and practices to not have the unintended consequences of unnecessarily overriding client rights, and client opportunities to maximise their autonomy and enjoyment of life.

### **Question B - Early stages on the dementia pathway**

Please answer these questions on pp. 39-40.

- i) What comments do you have on the above possible strategies, and how to implement them?
- ii) What other strategies could be added?
- iii) What examples of good practice can you identify?
- iv) What strategies can you suggest to ensure that the interests of special needs groups are met? (Special needs groups include Indigenous people, people of cultural and linguistic diversity, homeless people, people with Down syndrome, and people with younger onset dementia).
- v) For your organisation or sector to address the issues raised, what:
  - do you currently do?
  - could you do?

### **C. Middle stages on the dementia pathway**

#### **Introduction**

Ideally, people will have commenced their journey on the quality dementia pathway while they were in the early stages of dementia. As their dementia progresses, they will already have been introduced to the service system and know how to find out more as their needs change.

However, for some people, their first contact with a dementia diagnosis and the service system comes when they are in the middle stages of dementia. It is important that these people 'catch up' with the knowledge and actions which would ideally have occurred in prior years.

Services need to be co-ordinated, accessible and flexible to meet the specific needs of people in the middle stage on the dementia pathway.

Some people with dementia will exhibit severe behavioural and psychological signs and symptoms of dementia; these people may need highly specialized services, and staff need to be highly skilled in working effectively with them.

About half the people in the middle stages on the dementia pathway live in their own homes, or in the home of their carer. The remainder live in residential facilities; for example people in these middle stages can have their accommodation needs met in some Supported Residential Services (SRS) accommodation, with external support for the resident and/ or the staff.

Appendix 3 provides more detail of this stage on the pathway of dementia.

**Issues**

1. Identification of dementia in the middle stage of the pathway likely means that a person with dementia and their carers have not yet accessed available services and support, for example respite.
2. There are waiting lists for diagnosis and services, including ACAS assessment, and community support from basic HACC services through to Community Aged Care Packages (CACPs) and Linkages. Waiting for support can increase the pressure on informal carers, and lead to lost opportunities to access resources and supports that could assist a person with dementia.
3. Services for people with dementia and their families and carers can lack co-ordination, and establishing services requires dealing with a number of health professionals and support staff.
4. The service system is seen as complex by many.
5. Respite services are not always appropriate and flexible enough to meet needs.
6. People with dementia may exhibit behaviours of unmet need (described by health professionals as challenging behaviours, or behavioural and psychological signs and symptoms of dementia – BPSSD).
7. Providing timely and appropriate access to new information is a challenge.

**Desired Outcome**

People in the middle stages on the dementia pathway, and their carers, receive coordinated, accessible and flexible quality services responsive to their diverse needs.

<p><b>Prompt:</b> What are <b>your</b> two most important suggested strategies to meet this desired outcome, given the above issues?</p> <p>1. .....</p> <p>2. .....</p>
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**Possible Strategies**

*Forward planning*

1. As appropriate, support the work of the Public Advocate to increase awareness in the community about the benefits of planning for the future, taking out powers of attorney, and organising advanced care directives.

### *Service development and enhancement*

2. Focus on moving people into a continuum of quality of care, including flexible respite, and a co-ordinated and simplified service system. Promote a reduction in program boundaries, and care tasks delivered by one carer where possible, rather than a number of carers.
3. Seek to work with the Commonwealth Government on its policies and programs, to:
  - a) Simplify, and co-ordinate access to, the service system, including HACC and CACPs<sup>60</sup>.
  - b) Support people in locating appropriate services.
  - c) Reduce waiting times for services.
  - d) Increase support for those on waiting lists.
  - e) For example boost the case manager role outlined in the budget<sup>61</sup>, or target people for ongoing support, such as CALD, people living on their own, people in rural and remote areas, and people with younger onset dementia<sup>62</sup>.
4. Seek to utilise waiting lists for CACPs and other programs, to access people in the early stages of dementia who could benefit from supports other than the package for which they are waiting. Where people wait longer for services, their needs may be more likely to change; to identify changing needs, waiting lists could be accessed through the Aged Care Assessment Service (ACAS) teams or the agencies holding the waiting lists<sup>63</sup>.
5. For behaviours of unmet need (described by health professionals as challenging behaviours, or behavioural and psychological signs and symptoms of dementia - BPSSD):
  - a) Promote a holistic approach, including pain management and dental health.
  - b) Work across DHS program areas to develop training for various groups of staff, including mental health, acute and sub-acute, care for people living independently in the community, and residential care services.

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60. The Commonwealth Government review of community care, *A New Strategy for Community Care – The Way Forward*, indicates there will be renegotiation of Commonwealth - state HACC agreements. This provides an opportunity for Victoria to promote the needs of people with dementia and their carers being considered in renegotiation of agreements. An intended outcome aim of the review is to streamline community care programs, and simplify access to the system through adopting common program arrangements in areas such as assessment, access, quality, data development, and planning. The Commonwealth Government Department of Veterans' Affairs also provides programs of Veterans' Home Care, and Convalescent Care in hospitals. Data on the number of veterans with dementia receiving such services appear to be limited.

61. For people in the earlier stages of dementia, the role of ACAS in facilitating access to the service system may be crucial. The 2004/05 Commonwealth Government Budget provides additional funding to ACAS to maintain a focus on timely assessment, increase assessment activity, and increase the level of care management for frail older people with complex care needs.

62. It was hoped the Commonwealth Government review of community care, *A New Strategy for Community Care – The Way Forward*, could: facilitate case management support for individuals with dementia and their carers to enable them to remain in the community; target programs for people from diverse cultural and linguistic backgrounds for whom the prospect of placing a relative in residential care is unacceptable. However there seems to be little scope for targeting the particular needs of people with dementia and their families and carers in the review outcomes.

63. The Commonwealth Government in August 2004 released its review of community care, *A New Strategy for Community Care – The Way Forward*. The review provides for some 35,000 CACP places, and over 3,224 EACH places, to be available by 2006.

- c) Encourage appropriate, responsive and timely care and management in hospitals, continuing care, respite care, and aged care facilities, of older people with complex needs and people with cognitive impairment, including reducing the use of physical or chemical patient restraints which increases the risk of adverse events.
  - d) Promote availability of specialized care, usually provided by Aged Persons Mental Health Services, for people with severe BPSSD.
6. Promote high quality nutrition, hydration and dental health care practices for people with dementia<sup>64</sup>.
  7. Seek to encourage options for travel and mobility such as community transport.

***Support for people with dementia and their carers***

8. Encourage on-going monitoring of the needs of people with dementia and their families and carers, for example how can carers be best supported at this time; is there knowledge of the available options regarding day activities, respite, and residential care.
9. Continue to work with the DHS Continuing Care Program to maintain awareness of the needs of people with dementia and their families and carers in: care for older people in health services; development of policy and practice guidelines; accessibility of palliative care to people with dementia; and respect for patient choices and wishes.

***Respite and residential accommodation***

10. Use appropriately skilled and experienced bilingual bicultural people and bilingual personal carers to assist in the process of accessing appropriate care, and using appropriate respite.
11. Promote appropriate policy and practice in SRSs for residents with a diagnosis of dementia and their families, and other health care providers. Seek opportunities to provide support to SRS operators, for example through the provision of training opportunities, advice and written resources<sup>65</sup>.

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64. For example, see the dental health booklet *Oral Health for Older People. A Practical Guide for Aged Care Services*, Department of Human Services 2002.

65. For example the Boroondara PCP project on the health needs of residents of SRSs. The South Australian Government announced a similar project in 2004 on comprehensive assessments and care provision for residents of Special Residential Facilities (SRFs).

### **Question C – Middle stages on the dementia pathway**

Please answer these questions on pp. 40-42.

- i) What comments do you have on the above possible strategies, and how to implement them?
- ii) What other strategies could be added?
- iii) What examples of good practice can you identify?
- iv) What strategies can you suggest to ensure that the interests of special needs groups are met? (Special needs groups include Indigenous people, people of cultural and linguistic diversity, homeless people, people with Down syndrome, and people with younger onset dementia).
- v) For your organisation or sector to address the issues raised, what:
  - do you currently do?
  - could you do?

## **D. Late stages on the dementia pathway**

### **Introduction**

Some people with dementia may die of other conditions before they progress to the severe stages of dementia. For those who live to the later stages of dementia, their direct service needs are likely to increase, as are the needs of people caring for them. Maintaining people with dementia in their own homes is a primary objective, but most people reaching the later stages of dementia will require such high levels of care that their needs may best be met in residential aged care facilities<sup>66</sup>. It is unlikely that people in the later stages on the dementia pathway can have their accommodation needs met in Supported Residential Services (SRS) accommodation, without substantial, regular, external support for resident and/ or staff.

Some people will exhibit severe behavioural and psychological signs and symptoms of dementia early in this stage of dementia; these people may need highly specialized services, and staff need to be highly skilled in working effectively with them. Behaviours of unmet need (or BPSSD) diminish as a person in the late stages of dementia becomes more dependent on others.

Special issues emerge at end of life for people with dementia, and their families and carers.

Appendix 3 provides more detail of this stage on the pathway of dementia.

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66. AIHW (2004) suggests that at the end of 2002, 50% of permanent residents in residential aged care facilities possibly had dementia, and 31% probably had dementia. The length of stay in residential aged care by people with dementia is on average longer than stays by others; in 2001/02, people with possible or probable dementia accounted for 80% of occupied bed days by permanent residents (AIHW 2004, *The impact of dementia on the health and aged care systems*, p. xiii).

## Issues

1. Transitions from living at home to residential care can be difficult and challenging for people with dementia, and their families and carers.
2. People with dementia may exhibit behaviours of unmet need (described by health professionals as challenging behaviours, or behavioural and psychological signs and symptoms of dementia - BPSSD).
3. Families and carers may increasingly grieve the loss of the person they know.
4. Residential care may be hindered by systemic issues such as: untrained staff; proposed changes to Resident Classification Scale (RCS) funding models announced by the Commonwealth Government including development of a specific supplement for people with dementia, and behaviours of unmet need<sup>67</sup>; inadequate staffing and staff mix to meet the needs of people with BPSSD, including psychosocial interventions; residential aged care environments not planned to meet the needs of people with dementia.
5. People with dementia and their families and carers face end of life.
6. In the late stage of the dementia pathway, as people return to their primary language, culturally sensitive care and services are vital.

## Desired Outcome

Quality of life is maximised for people with dementia, and families and carers receive support and empathy as their loved one goes through the final stages of dementia to death.

**Prompt:**

What are **your** two most important suggested strategies to meet this desired outcome, given the above issues?

1. ....
2. ....

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67. The Commonwealth Government *Review of Pricing Arrangements in Residential Aged Care* (the Hogan Review) acknowledges the prevalence of dementia and the associated costs of care and support. The review has led to work reconfiguring the Resident Classification Scale (RCS) from eight to three categories of High, Medium and Low care needs. These changes are planned to be implemented in 2005. The Commonwealth Government will also introduce a Dementia Supplement. To support these changes, and given the 2004 election commitment of \$200 million over four years for Dementia as a Health Priority, focussing on research, improved care, additional care in the community, and dementia education and training, it is likely that the Commonwealth Government will:

- Examine possible changes to *The Standards and Guidelines for Residential Aged Care Services* to include requirements of care for people with dementia.
- Develop tools and guidelines for residential care workers.
- Provide training in dementia care to residential and community aged care staff.

## **Possible Strategies**

### *Transitions from living at home to residential care*

1. Support ACAS in identifying the need for support for the person with dementia and for the carer at the time of transition, and making appropriate referrals.
2. Support providers in delaying transitions from living at home to residential care, for example more flexible respite including night respite.
3. Identify and promote innovative community respite models and the use of the residential care system before a crisis occurs.
4. Support programs for families at the time of transition to residential care. Promote practice which assists carers to trust the service system, and relinquish their caring role. Identify providers who currently provide this service, and promote such practices where and as appropriate.

### *Service development and enhancement*

5. Work across DHS program areas to enhance training for various groups of staff in metropolitan and rural areas, including mental health, acute and sub-acute, care for people living independently in the community, and residential care services.
6. Encourage appropriate, responsive and timely care and management in hospitals, continuing care, respite care, and aged care facilities, of older people with complex needs and people with cognitive impairment, including reducing the use of physical or chemical patient restraints which increases the risk of adverse events.
7. Promote a holistic approach, including pain management and dental health<sup>68</sup>, to behaviours of unmet need (described by health professionals as challenging behaviours, or behavioural and psychological signs and symptoms of dementia – BPSSD).
8. Promote availability of specialized care, usually provided by Aged Persons Mental Health Services, for people with severe BPSSD.
9. Continue to work with the DHS Continuing Care Program to maintain awareness of the needs of people with dementia and their families and carers in: care for older people in health services; development of policy and practice guidelines; accessibility of palliative care to people with dementia; and respect for patient choices and wishes.

### *Support and counselling for families and carers*

10. Promote readily accessible support and counselling for families and carers, including grief counselling for what is lost, information about responding to behaviours of unmet need, support in the community, and support based at residential care facilities.

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68. For example, educate unpaid carers and residential aged care staff in dental health care of people with dementia. The booklet *Oral Health for Older People. A Practical Guide for Aged Care Services*, Department of Human Services 2002, is a useful aid.

11. Promote availability of information about complaints processes, including the Health Services Commissioner, and post grievance support and counselling.

#### ***Respite and residential accommodation***

12. Continue to seek change in negotiations with the Commonwealth Government on systemic issues that form barriers to flexible respite in the residential care system.
13. Promote appropriate policy and practice in Supported Residential Services (SRSs) for residents with a diagnosis of dementia and their families, and other health care providers. Seek opportunities to provide support to SRS operators, for example through the provision of training opportunities, advice and written resources. Facilitate transfer to more appropriate, specialised, supported accommodation.
14. Continue to lobby the Commonwealth Government for adequate levels of care funding and an appropriate RCS funding model for people with dementia, including adequate funding for the proposed Dementia Supplement.
15. Research literature and practice on appropriate residential care environments for people with dementia, identify the critical principles, produce user friendly and practical hints and tips on creating dementia friendly social and physical environments, disseminate the hints and tips to relevant stakeholders, and seek to establish a demonstration model/s<sup>69</sup>.
16. Promote high quality nutrition and hydration practices, including the use of finger food where appropriate, and senior friendly accessible food where opening packaged food is required.
17. Identify existing dementia specific wings or units in residential care facilities.
18. Identify opportunities to promote training in dementia care and management.
19. Identify appropriate respite and residential options especially in rural areas, for people with behaviours of unmet need.

#### ***Cultural and linguistic diversity***

20. Use appropriately skilled and experienced bilingual bicultural people and bilingual personal carers to assist in the process of accessing appropriate care, and using appropriate respite.
21. Identify and promulgate service models to meet the diversity of need.
22. Identify and promulgate good practice literature and service delivery models.

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69. The DHS Aged Care *Public sector residential aged care policy* (2004), in considering new models of care, identifies building design as one variable to achieve desired outcomes, such as improved quality of care outcomes for residents.

### **Question D – Late stages on the dementia pathway**

Please answer these questions on pp. 42-44.

- i) What comments do you have on the above possible strategies, and how to implement them?
- ii) What other strategies could be added?
- iii) What examples of good practice can you identify?
- iv) What strategies can you suggest to ensure that the interests of special needs groups are met? (Special needs groups include Indigenous people, people of cultural and linguistic diversity, homeless people, people with Down syndrome, and people with younger onset dementia).
- v) For your organisation or sector to address the issues raised, what:
  - do you currently do?
  - could you do?



**For photocopy or pull-out pp. 37 - 44**

**QUESTIONNAIRE: YOUR COMMENTS ON PROPOSED STRATEGIES FOR  
DEMENTIA CARE AND SUPPORT IN VICTORIA 2005 AND BEYOND**

The input of individuals and organisations is sought on suggestions to build on dementia policy and practice in Victoria, as outlined above. Organisations may wish to agenda this document for discussion at a regular or extraordinary meeting.

**Please return your questionnaire before Friday 25 February 2005.**

**Name:** .....

**Title:** .....

**Organisation:** .....

**Address:** .....

.....

**Telephone:** .....

**Email:** .....

You may not be able or wish to provide feedback on every question. Please answer those questions you wish to.

**Question A - Preventing and reducing the risks of dementia - healthy and active living**

- i) What comments do you have on the possible strategies in this consultation paper for preventing and reducing the risks of dementia, the impact of healthy and active living, and how to implement these strategies? (See pages 18 - 20).

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- ii) What other strategies could be added for preventing and reducing the risks of dementia, including the impact of healthy and active living?

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**Question B – Early stages on the dementia pathway**

i) What comments do you have on the possible strategies in this consultation paper for the early stages on the dementia pathway, and how to implement them? (See pages 21 - 27).

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ii) What other strategies could be added in the early stages of the dementia pathway?

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iii) What examples of good practice can you identify in the early stages of the dementia pathway?

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iv) What strategies can you suggest to ensure that the interests of special needs groups are met in the early stages of the dementia pathway? (Special needs groups include Indigenous people, people of cultural and linguistic diversity, homeless people, people with Down syndrome, and people with younger onset dementia).

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- v) For your organisation or sector to address the issues raised, what:
- do you currently do?
  - could you do?

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**Question C – Middle stages on the dementia pathway**

- i) What comments do you have on the possible strategies in this consultation paper for the middle stages of the dementia pathway, and how to implement them? (See pages 27 – 31).

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- v) For your organisation or sector to address the issues raised, what:
- do you currently do?
  - could you do?

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**Question D – Late stages on the dementia pathway**

- i) What comments do you have on the possible strategies in this consultation paper for the late stages of the dementia pathway, and how to implement them? (See pages 31 - 35).

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- ii) What other strategies could be added for the late stages of the dementia pathway?

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**Question E - Other comments**

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Please return your questionnaire by **Friday 25 February 2005**, to:

Diane Calleja  
Dementia Portfolio and Support for Carers  
Aged Care, Department of Human Services

Email: [di.calleja@dhs.vic.gov.au](mailto:di.calleja@dhs.vic.gov.au)  
Fax: (03) 9616 8682  
Address: 10<sup>th</sup> Floor  
555 Collins Street  
Melbourne 3000

## Appendix 1

### Victorian Dementia Working Group

Teorrah Kontos	Cognitive Dementia and Memory Service (CDAMS)
Lynette Moore	Alzheimer's Australia Vic (AAV)
Ronda Schultz	UnitingCare Community Options
Mark Yates	Geriatrician
Kuruvilla George	Deputy Chief Psychiatrist Department of Human Services (DHS)
Diane Calleja	Aged Care Branch DHS

#### Coopted Member

Carol Pyke	Continuing Care DHS
------------	---------------------

### Victorian Dementia Reference Group

Jane Herington, Chair	Director Aged Care DHS
Yvonne Arthur	Municipal Association of Victoria (MAV)
Maria Bohan	Carers Victoria
Jill Clutterbuck	Australian Nursing Federation (ANF) Victoria Branch
Cheryl Donohue/ Teorrah Kontos	Cognitive Dementia and Memory Service (CDAMS)
Pauline Fegan/ Margaret Barrett	Hospital Services Union of Australia (HSUA)
Pamela Forster	Commonwealth Government Dept Health & Ageing
Peter Gogorosis	Ethnic Communities' Council of Victoria (ECCV)
Ila Howard	Brotherhood of St Laurence (BSL) Banksia Respite Care & Day Services
Sandy Keppich-Arnold	Aged Psychiatry Services
Kevin McInerney	Benetas
Judy McKee/ Pauline Donaldson	Aged Care Assessment Service (ACAS)
Lynette Moore	Alzheimer's Australia Vic (AAV)
Barbara Potter AM	Carer
Richard Rosewarne	Researcher
Ronda Schultz	UnitingCare Community Options
Bess Yarram	Koori HACC Statewide Network
Mark Yates	Geriatrician
Kuruvilla George	Deputy Chief Psychiatrist DHS
Janet Laverick, Susan Race, Carol Pyke	Continuing Care DHS
Catherine Thompson	Manager Service Development, Aged Care Branch DHS
Diane Calleja	Service Development Aged Care Branch DHS

## Appendix 2

### Major Forms of Dementia

“Dementia” is not a distinct clinical syndrome. It is a descriptive term. There are known to be 168 causes of dementia. The dementias listed below are known as primary dementias, that is, they are due to primary neuronal degeneration and are therefore not reversible. There are a number of reversible dementias which include: metabolic disturbances (for example thyroid); vitamin deficiencies (B12); dementias which arise from structural/anatomic disturbance (for example tumours, normal pressure hydrocephalus); and dementias which arise from alcohol or drug abuse (not always reversible but may be, especially alcohol).

#### **Dementia:**

- Is acquired, that is there is a change in a person’s cognitive capacity.
- Is progressive, that is there is a progressive decline and loss of intellect over time.
- Is multidimensional, that is dementia affects a number of areas of cognition – deficits in memory plus at least one other cognitive function, such as difficulty finding words or spatial disorientation.
- Occurs in the absence of clouding of consciousness, that is dementia is distinguished from a confusional or delirium state which is short lasting and is usually due to a metabolic or infective insult on the body, such as a Urinary Tract Infection (UTI).

There are many forms of **dementia**, the most common of which are listed below. **Depression** and **delirium**, which commonly mimic dementia, are also described.

#### **Alzheimer’s disease, or Dementia of the Alzheimer’s type (DAT)**

- Most common cause of dementia in Australia.
- Gradual but inevitable deterioration occurs in cognitive ability over time.
- Predominant feature is memory loss (rapid forgetting).
- Also affects other brain functions (for example language, reasoning and judgement).
- Average duration is 6 – 10 years.
- O’Brien et al (2000: 23, 247) consider that possible risk factors especially for late-onset DAT include APOE gene on chromosome 19, Down syndrome, ethnic background, low education, low intelligence, smoking history, environmental stimulation, activity levels, high fat high calorie diet, and diabetes.

#### **Vascular Dementia (VD) or Multi-infarct Dementia (MID)**

- Term describing forms of dementia caused by damage to the blood vessels leading to the brain.
- Symptoms can occur suddenly following stroke/Cardio Vascular Arrest (CVA), or over time through a series of small strokes.
- Abrupt onset, stepwise course.
- Initially cognitive deficits are patchy. However as the volume of infarcted tissue increases, the functional consequences become more generalised and apparent.
- Depression and mood swings are common.
- O’Brien et al (2000: 247) consider that the risk factors include hypertension, obesity, hyperlipidaemia, smoking and diabetes.

### **Lewy Body Disease (LBD)**

The clinical picture is similar to DAT. LBD is clinically distinguishable by:

- Course which is usually more rapid than DAT, at 6-7 years.
- Marked fluctuations in cognitive impairment, alertness and/or behavioural disturbance; greater impairment of attention (for example digit span), visuospatial ability (for example drawing a clock), and executive function (for example fluency).
- Increased prevalence of mild extrapyramidal features, such as rigidity, tremor and gait abnormalities.
- Increased prevalence of psychiatric symptoms, such as hallucinations, delusions, depression and paranoia.
- Electro encephalogram (EEG) abnormalities early in the disease.
- Incontinence early in the disease.

### **Fronto-temporal Dementia (FTD)**

Core diagnostic features include:

- Insidious onset and slow progression.
- Early loss of personal awareness, such as neglect of hygiene and grooming.
- Early loss of social awareness, such as loss of social skills and behaviours, inappropriate behaviours such as shop lifting.
- Early signs of disinhibition, such as unrestrained sexuality, violent behaviour, inappropriate jocularity.
- Mental rigidity and inflexibility, that is becoming stimulus bound.
- Hyperorality, that is over-eating, smoking or alcohol consumption.
- Perseverative and stereotyped behaviour, with mannerisms such as clapping, singing, and ritualistic preoccupation, for example irrational fixations.
- Distractibility, impulsivity and impersistence.
- Early loss of insight into own actions.

### **Creutzfeldt-Jakob Disease (CJD), or Spongiform Encephalopathy**

- Dementia is caused by prions, abnormal proteins and infectious agents that attack the central nervous system (CNS) and then invade the brain.
- Course is extremely rapid, with death occurring within six months to a year.
- The first weeks see fatigue, depression, anxiety, and forgetfulness, followed by profound intellectual impairment and neurological defects as the disease takes its course.
- Hallucinations and delusions often present.
- The pathology is neuronal degeneration, proliferation of astrocytes, and spongy appearance of grey matter.
- The aetiology is:
  - Sporadic.
  - Familial.
  - Iatrogenic.
  - Variant Bovine Spongiform Encephalitis (BSE).

### **Alcoholic Dementia, or Alcohol Related Dementia**

- A condition of significant mental and personality deterioration occurring after years of alcohol abuse.
- Features widespread cognitive deterioration without the profound amnesic syndrome of Korsakoff's.
- Memory deficits.
- Typically associated with frontal lobe pathology.

- Sometimes display symptoms typical of Korsakoff's syndrome and vice versa, suggesting that they have sustained more than one kind of alcohol related brain damage.
- Problems with concentration and memory and slowed mental processing are the usual earliest cognitive symptoms.
- Chronic alcohol consumption results in neuronal loss.
- Computed Tomography (CT) evidence of atrophy and neuropsychological impairment is common in people who are alcoholics.

### **Alcoholic Cerebellar Degeneration**

- Probably the most common set cause of acquired ataxia, alcoholic patients may develop a chronic cerebellar syndrome either as a sequel of Wernicke's Syndrome or as a distinct clinical entity.
- A long history of alcohol abuse is obtained, onset is gradual, and symptoms often stabilise.
- Ataxia of gait.

### **Korsakoff's Syndrome**

- The most striking deficit associated with alcoholism is the gross memory impairment of Korsakoff's.
- Evidence of diencephalic amnesia.
- Typically affects alcoholics with a long drinking history.
- When the person's diet is insufficient to meet the body's needs those regions of the brain that are more thiamine dependent will suffer impaired neuronal function.

### **Head Injury**

- The principal causes of head injury include road traffic accidents, falls, assaults and injuries in the home, during sports and at work.
- Brain damage occurs both at impact and as a result of the development of secondary complications. Management aims at preventing the development of secondary brain damage. Most people make a rapid and full recovery.
- People who sustain head injuries are more likely to sustain subsequent head injuries, and there is a strong suggestion in the literature that the effects of even very mild head injuries may be cumulative.

### **Cumulative Brain Damage**

- The effects of repeated neuronal damage are cumulative.
- When this exceeds the capacity for compensation, permanent evidence of brain damage ensues.
- This is well recognised in boxers.
- Dementia may also occur from repeated head injury.

### **Subcortical Dementia**

The distinction between cortical and subcortical dementias is essentially a behaviour based clinical distinction but it is supported by several other characteristics. For example, neuropsychological assessment shows that memory and visual spatial deficits in sub-cortical dementia tend to be less severe than in the cortical dementias and differ in their nature, while most language and practic functions are almost universally spared (Deutsch Lezak M., Oxford University Press 1995:222).

- Subcortical structures of the brain are affected, that is the white matter and association cortices.

- Cognitive deficits result from disruption of connections between networks and systems, specifically the substantia nigra, neostriatum, thalamus, midbrain, and frontal cortex.
- Commonly involves motor systems.

#### *Parkinson's Disease (PD)*

- Between 25-40% of people with Parkinson's Disease develop a dementia.
- The pathology is cell loss and Lewy bodies in the substantia nigra producing dopamine deficiency.
- Cognitive deficits include:
  - o Psychomotor slowing, bradyphrenia.
  - o Loss of cognitive flexibility.
  - o Reduced new learning.
  - o Constructional problems.

#### *Huntington's Disease*

- Hallucinations and delusions may occur early.
- Movement disorder occurs early.
- Memory impairment occurs early.
- There is executive dysfunction with reduced judgement, planning and organisation capacities.
- **A language deficit may occur.**

#### *AIDS (Acquired Immunodeficiency Syndrome) Dementia Complex (ADC)*

- Human Immunodeficiency Virus (HIV) can directly cause certain central nervous system (CNS) complications.
- HIV-related cognitive disturbance occurs later in HIV positive patients (Stage 4 when there is symptomatic illness, for example pneumonia, dementia or cancer).
- ADC (also known as HIV associated dementia – HAD) has a prevalence rate of about 15% in AIDS patients.
- Course is usually insidious, and occurs over months rather than years, usually with rapid progression after early clinical signs are evident.

*Other conditions may mimic dementia and need to be treated and managed early. Two of the most common of these conditions are:*

### **1. Depression**

- Depression in older people may affect cognition, which is termed depressive pseudo-dementia (DPD), or dementia syndrome of depression.
- An accurate diagnosis is essential, as DPD is a reversible syndrome, with many responding well to therapy and/ or antidepressants.
- It is estimated that between 35 – 50 % of people with DAT have DPD.
- Depression and dementia may present a clinically similar picture including:
  - Impaired concentration.
  - Memory deficits.
  - Loss of self care.
  - Social withdrawal.
  - Psychomotor retardation, for example, movements and reflexes.
  - Common in older people.
- DPD is different to dementia. For example, with DPD:
  - People often self-refer.

- Onset is relatively abrupt, with patients often able to date it, and presenting within 2-4 months of cognitive loss.
- Behaviour during testing is often hypervigilant and suspicious, with fluctuating co-operation, and test performances can fluctuate daily.
- Affect is flattened, with sleep and appetite disturbance but no nocturnal confusion.

Psychiatrically depressed persons in the depths of their depression may display a pattern of dysfunctional behaviour that appears so much like dementia that it has been labelled Pseudo Dementia.

## **2. Delirium**

- Delirium is a description of a syndrome, and it is important to know what causes it.
- Features include: clouding of consciousness, and decreased capacity to shift focus and sustain attention to environmental stimuli.
- At least two of the following have to be present:
  - Perceptual disturbance, for example hallucinations, illusions.
  - Speech that is sometimes incoherent.
  - Sleep-wake cycle disturbances and insomnia/ daytime drowsiness.
  - Increased or decreased psychomotor activity.
- Disorientation and memory impairment exist.
- Clinical features develop over a short period (hours to days), and fluctuate over the course of a day.
- Evidence based: from history, physical examination, or laboratory tests, of a specific organic factor judged to be aetiologically related to the disturbance.

*Main sources: Teorrah Kontos, Cognitive Dementia and Memory Service Clinic (CDAMS) Peter James Centre, Burwood East  
Cheryl Donohue, CDAMS Austin & Repatriation Medical Centre, Heidelberg West*

## **Appendix 3**

### **Pathway of Dementia**

Dementia can be described in terms of a series of stages, from initial and mild symptoms to a terminal decline of the central nervous system. There is variation in the symptoms that can occur during the course of dementia, and the way dementia affects each individual. Changes as dementia progresses are hard to pinpoint and may differ with different types of dementia. While stages of the pathway of dementia vary for individuals in duration, characteristics and significant crossings, individual autonomy continues to decline. Eventually, the effects of damage to the brain tissue are cumulative, disabling and terminal.

The three major stages on the dementia pathway used in this consultation paper, and identified by authorities in dementia, follow.

#### **Early stages on the dementia pathway**

There is a subtle deterioration in a person's mental functioning, such as:

- getting lost on a familiar route,
- having a reduced attention span,
- becoming repetitive in conversation, and
- being anxious or suspicious about a partner's behaviour.

This is followed by the emergence of significant difficulties in daily living, for example:

- recognising close family and friends,
- having false memories,
- having poor judgement and problems thinking logically,
- having trouble dealing with money,
- having difficulty driving a motor vehicle, and
- having problems remembering the layout of their home.

At these early stages people have a capacity for insight, which is likely to cause distress. People commonly try to minimise or compensate for their difficulties. Some people may adjust daily activities and arrangements to mask problems, or become anxious, angry or distressed by symptoms.

#### **Middle stages on the dementia pathway**

In middle stages of dementia, a person may:

- have difficulty finding the right words in conversation,
- have fixed or temporary ideas that are not real,
- have uncharacteristic mood swings, or occasional outbursts of abusive language or violence,
- wander around their home or away from their home at random,
- become upset when faced with making changes, or
- need constant supervision.

While capacity for independent living is compromised, many older people living alone are able to continue doing so. Community care and support services can provide essential supports for daily living, particularly if the person's family and carers can provide consistent help. A break in familiar routines, such as a hospital admission after injury or illness, can result in disorientation in time and place, and precipitate a crisis

for the individual or care arrangements. Specific aged care health services and assessment services become essential to the care of individuals and support of families and carers.

### **Late stages on the dementia pathway**

In late stages of dementia, a person:

- needs complete assistance with eating and toileting and often personal care,
- may no longer recognise close family,
- may no longer do the things they enjoy,
- may no longer talk,
- may lose mobility,
- is likely to have medical complications of dementia, such as falls or urinary incontinence, or to develop pneumonia.

A person is dependent on others for management of their life. They may lose awareness of other people's identities, and a sense of self. The person is often placed in a residential aged care facility for the remainder of their life. While primary care is by nursing and other care staff, there is increasing focus on involving carers who wish to be involved in care and support of their loved one, or in other ways in the facility. Behaviours of unmet need (or BPSSD) diminish as a person in the late stages of dementia becomes more dependent on others.

Based on: Department of Human Services (1997)  
*Dementia Care in Victoria: Building a Pathway to Excellence*

## Appendix 4

### Services in Victoria for people with dementia and their carers

Stage on dementia pathway	Service and Title	Main clients	Program Title and Provider	DHS Program area/ other
Early	Early assessment/ diagnosis, support, referrals, information and links	People with dementia	CDAMS (and GPs, ACAS, HACC, etc referrals to CDAMS)	Continuing Care
	Early diagnosis, support, referrals, information and links	People with dementia	Dementia Support for Assessment Program - ACAS	Commonwealth Government
	Early identification and referrals	Including people with dementia	Home and Community Care	HACC
	Support, counselling, information and links	People with dementia and their carers	Support and Links, Memory Lane Café, HelpLine – Alzheimer's Australia Vic	Aged Care, HACC, City of Greater Geelong (up to June 2005), Commonwealth Government
	Support, counselling, information and links	Carers including of people with dementia	Services provided by Carers Vic	Aged Care, HACC, Mental Health, Disability Services
	Education	Families, carers and friends	Carer Education and Workforce Training (CEWT), Managing Change, Drawing the Threads, Information Sessions, Providing Care in your Own Home: Alzheimer's Australia Vic	Commonwealth Government, HACC, Allens Arthur Robinson Trust
	Respite and support for carers	Carers including of people with dementia	Support for Carers Program (SCP) and other programs - Carer agencies	Aged Care, HACC, Commonwealth Government
	Flexible support	Carers of people with dementia	Flexible Support for Carers of People with Dementia - Carer Respite Centres	Aged Care

<b>Stage on dementia pathway</b>	<b>Service and Title</b>	<b>Main clients</b>	<b>Program Title and Provider</b>	<b>DHS Program area/ other</b>
	Home care	Including people with dementia and their carers	Home and Community Care	HACC, Commonwealth Government
	Home care – special needs including CALD and indigenous: activity programs, support, information, respite and links	Including people with dementia and their carers	Home and Community Care	HACC
	Activity programs	Including people with dementia	Planned Activity Groups (PAGs) - Home and Community Care	HACC, Commonwealth Government
	Residential care	Including people with dementia	SRSs	Aged Care
	Residential care	Including people with dementia	Low level and high level aged care facilities service providers	Commonwealth Government
Middle	Assessment, diagnosis, support, referrals, information and links	People with dementia	CDAMS (and GPs, ACAS, HACC, etc referrals to CDAMS)	Continuing Care
	Diagnosis, support, referrals, information and links	People with dementia	Dementia Support for Assessment Program - ACAS	Commonwealth Government
	Identification and referrals	Including people with dementia	Home and Community Care	HACC
	Support, counselling, information and links	People with dementia and their carers	Support and Links, HelpLine - Alzheimer's Australia Vic	Aged Care, HACC, Commonwealth Government
	Support, counselling, information and links	Carers including of people with dementia	Services provided by Carers Vic	Aged Care, HACC, Mental Health, Disability Services

<b>Stage on dementia pathway</b>	<b>Service and Title</b>	<b>Main clients</b>	<b>Program Title and Provider</b>	<b>DHS Program area/ other</b>
	Education	Families, carers and friends	Carer Education and Workforce Training (CEWT), Managing Change, Drawing the Threads, Information Sessions, Providing Care in your Own Home: Alzheimer's Australia Vic	Commonwealth Government, HACC, Allens Arthur Robinson Trust
	Flexible support	Carers of people with dementia	Flexible Support for Carers of People with Dementia - Carer Respite Centres	Aged Care
	Support for agitated behaviours, including respite	Carers including of people with dementia	Care Links	Commonwealth Government
	Advice on agitated behaviours	Respite care staff and carers	National Dementia Behaviour Advisory Service (NDBAS) - Alzheimer's Australia	Commonwealth Government
	Respite and support for carers	Carers including of people with dementia	Support for Carers Program (SCP) and other programs - Carer agencies	Aged Care, HACC, Commonwealth Government
	Activity programs	Including people with dementia	Planned Activity Groups (PAGs) - Home and Community Care	HACC, Commonwealth Government
	Home care	Including people with dementia and their carers	Home and Community Care	HACC, Commonwealth Government
	Home care – special needs including CALD and indigenous: activity programs, support, information, respite and links	Including people with dementia and their carers	Home and Community Care	HACC

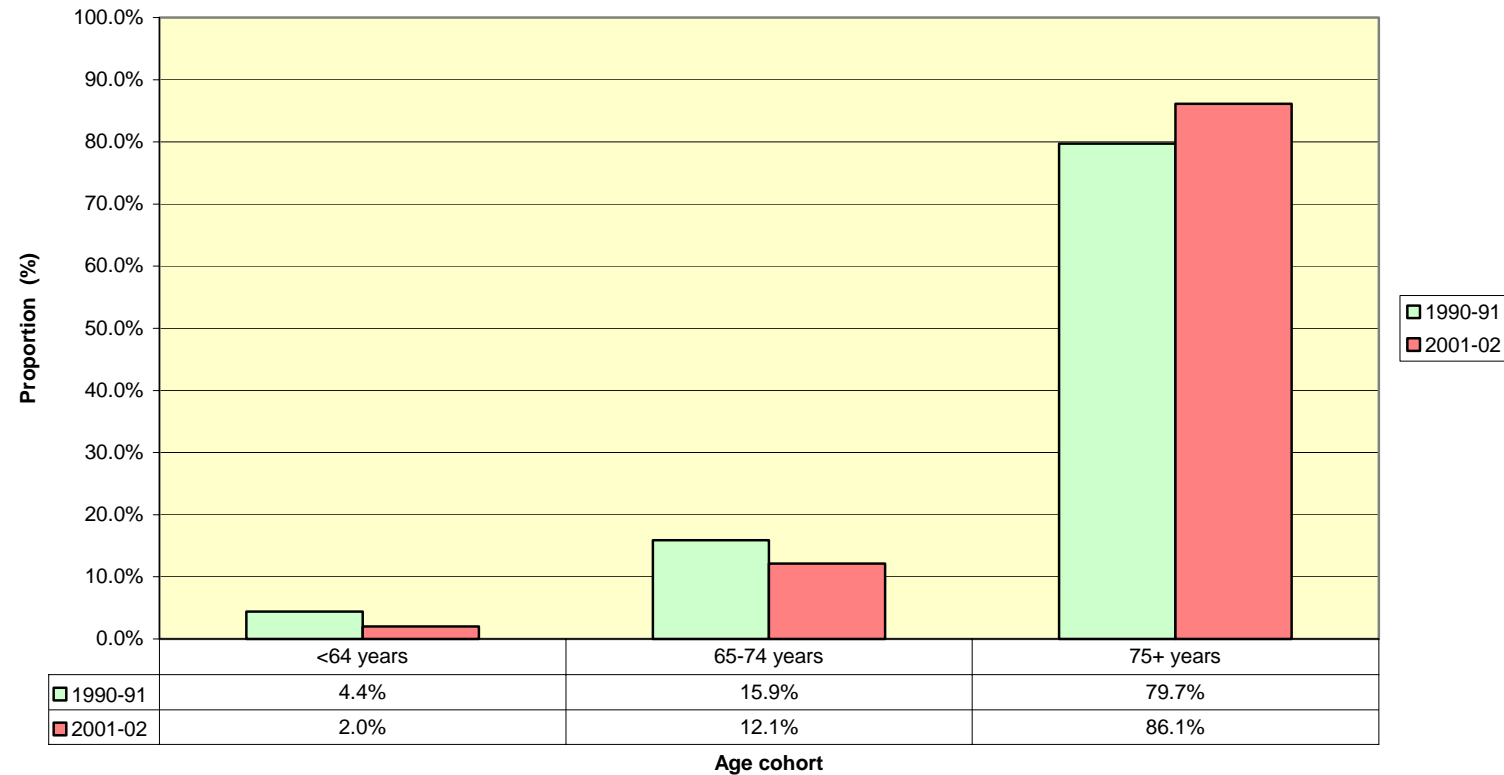
<b>Stage on dementia pathway</b>	<b>Service and Title</b>	<b>Main clients</b>	<b>Program Title and Provider</b>	<b>DHS Program area/ other</b>
	Support to live at home	Including people with dementia	Linkages – various providers	HACC
	Support with challenging behaviours: assessment, diagnosis, case management/ treatment, information, links, counselling, and referral to APMH residential care	Including people with dementia and their carers	Aged Persons Mental Health (APMH) Community Teams	Mental Health
	Residential care	Including people with dementia	SRSs	Aged Care
	Residential care	Including people with dementia	Low level and high level aged care facilities service providers	Commonwealth Government
Late	Support to live at home	Including people with dementia	CACPS – various providers	Commonwealth Government
	Residential care	Including people with dementia	Low level and high level aged care facilities service providers	Commonwealth Government
	Support with challenging behaviours: assessment, diagnosis, case management/ treatment, information, links, counselling, and referral to APMH residential care	People with dementia and their carers	Aged Persons Mental Health Community Teams	Mental Health
	Support for challenging behaviours, including respite	Carers of people with dementia	Care Links	Commonwealth Government
	Support, counselling, information and links	Carers of people with dementia	Support and Links, HelpLine - Alzheimer's Australia Vic	Aged Care, HACC, Commonwealth Government

<b>Stage on dementia pathway</b>	<b>Service and Title</b>	<b>Main clients</b>	<b>Program Title and Provider</b>	<b>DHS Program area/ other</b>
	Support, counselling, information and links	Carers including of people with dementia	Carers Vic	Aged Care, HACC, Mental Health, Disability Services
	Education	Families, carers and friends	Carer Education and Workforce Training (CEWT), Managing Change, Drawing the Threads, Information Sessions, Providing Care in your Own Home: Alzheimer's Australia Vic	Commonwealth Government, HACC, Allens Arthur Robinson Trust
	Support and counselling	Carers including of people with dementia	Palliative Care	Continuing Care

## Appendix 5

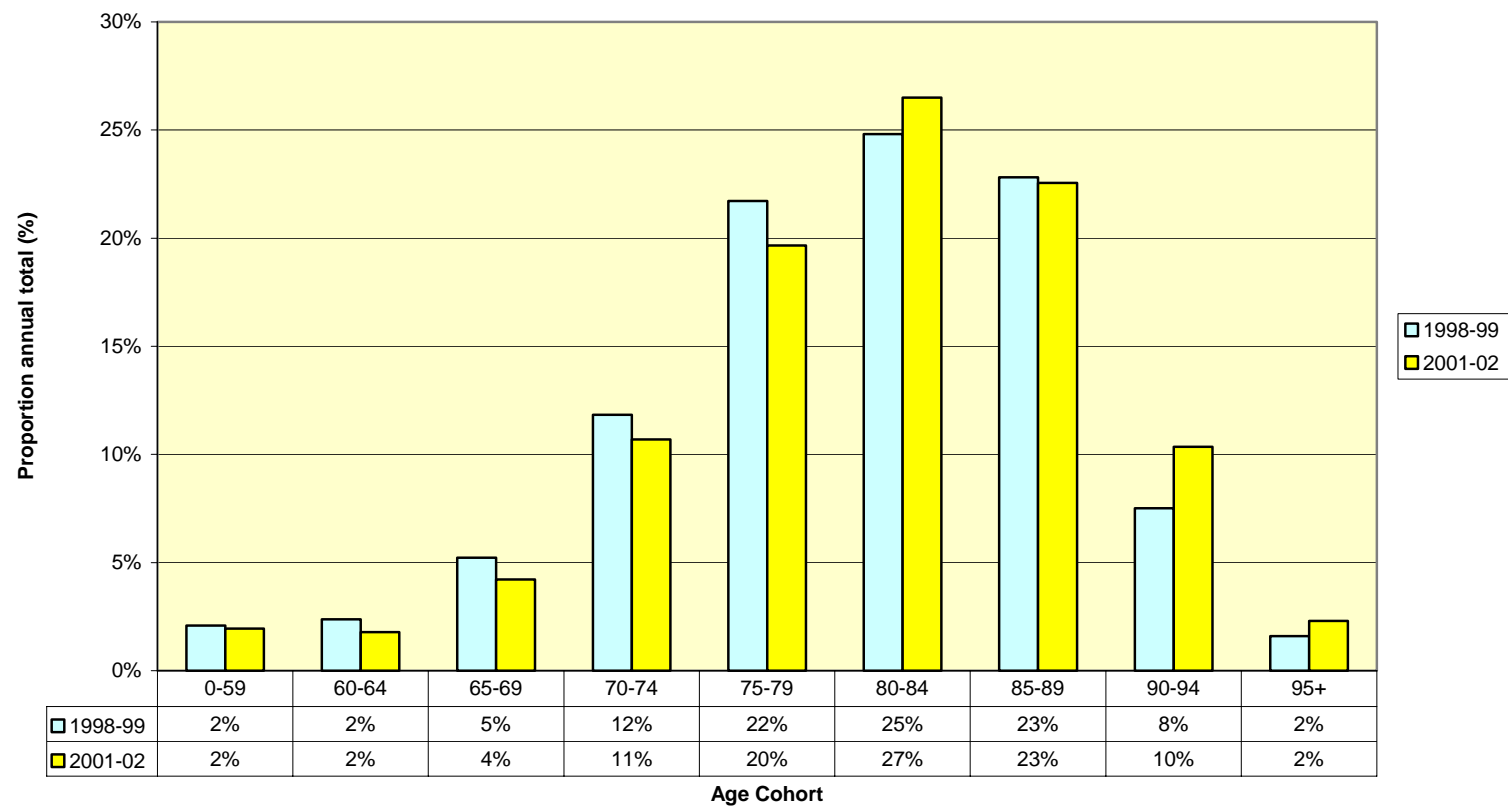
### Graphs 1-8: Impact of dementia on the health and aged care systems

#### 1. GP Patients with dementia survey, 1990-91 & 2001-02



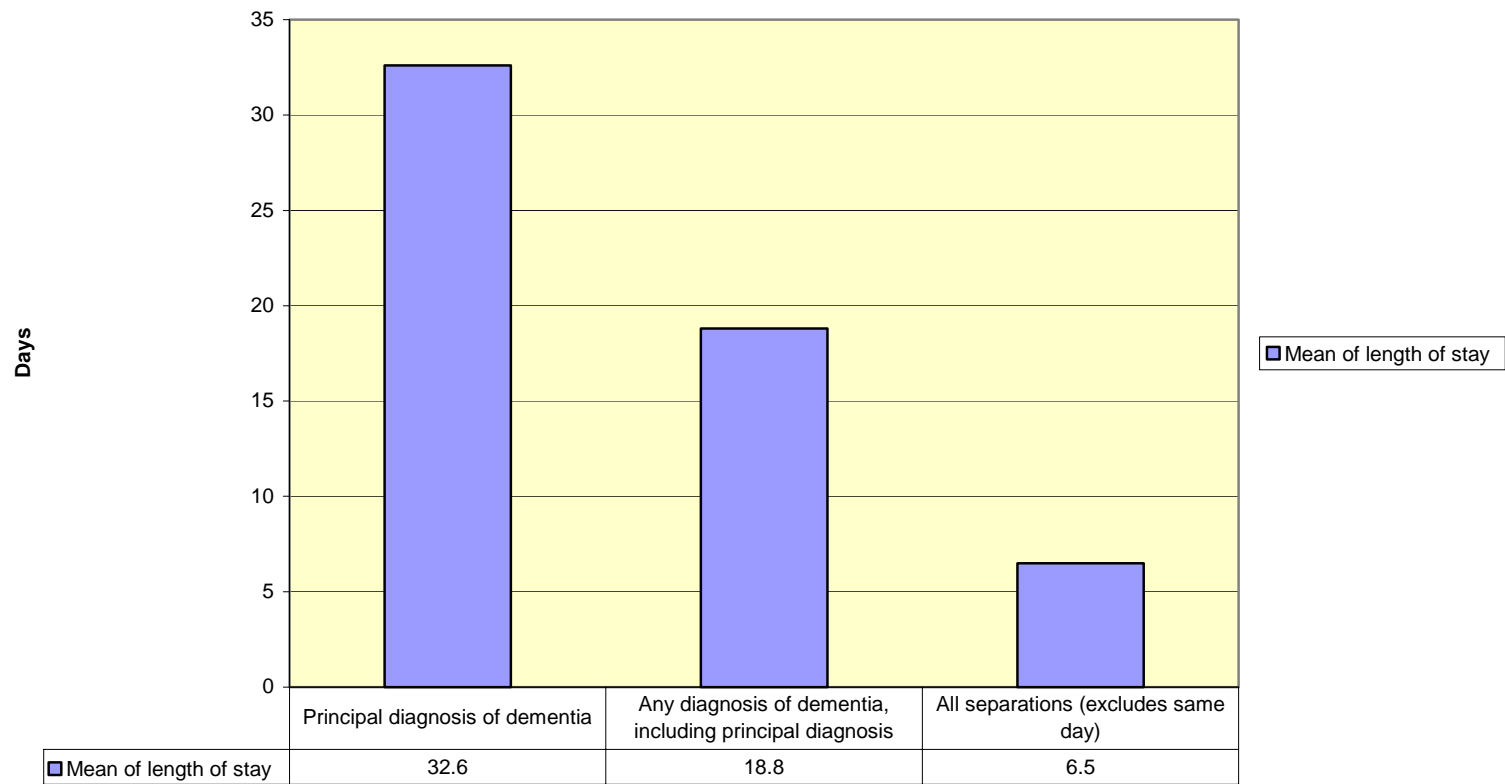
**Source:** AIHW (2004) *The impact of dementia on the health and aged care systems* - Data prepared by Policy & Analysis Unit, Aged Care Branch, Department of Human Services

## 2. Hospital Separations, Dementia and Age, Australia, 1998-99 & 2001-02



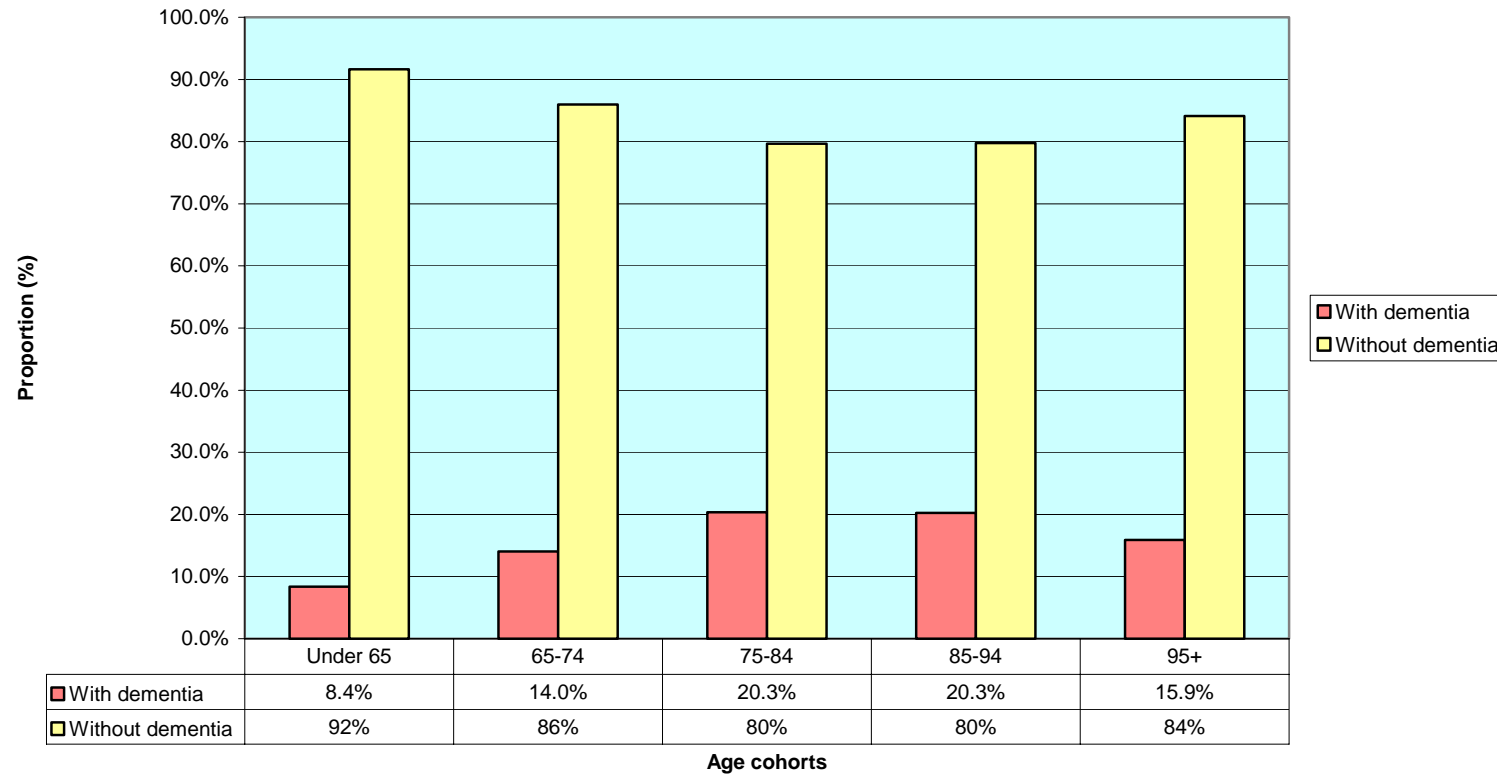
**Source:** AIHW (2004) *The impact of dementia on the health and aged care systems* - Data prepared by Policy & Analysis Unit, Aged Care Branch, Department of Human Services

### 3. Length of hospital stay by dementia diagnosis (excludes same day separations), 2001-02



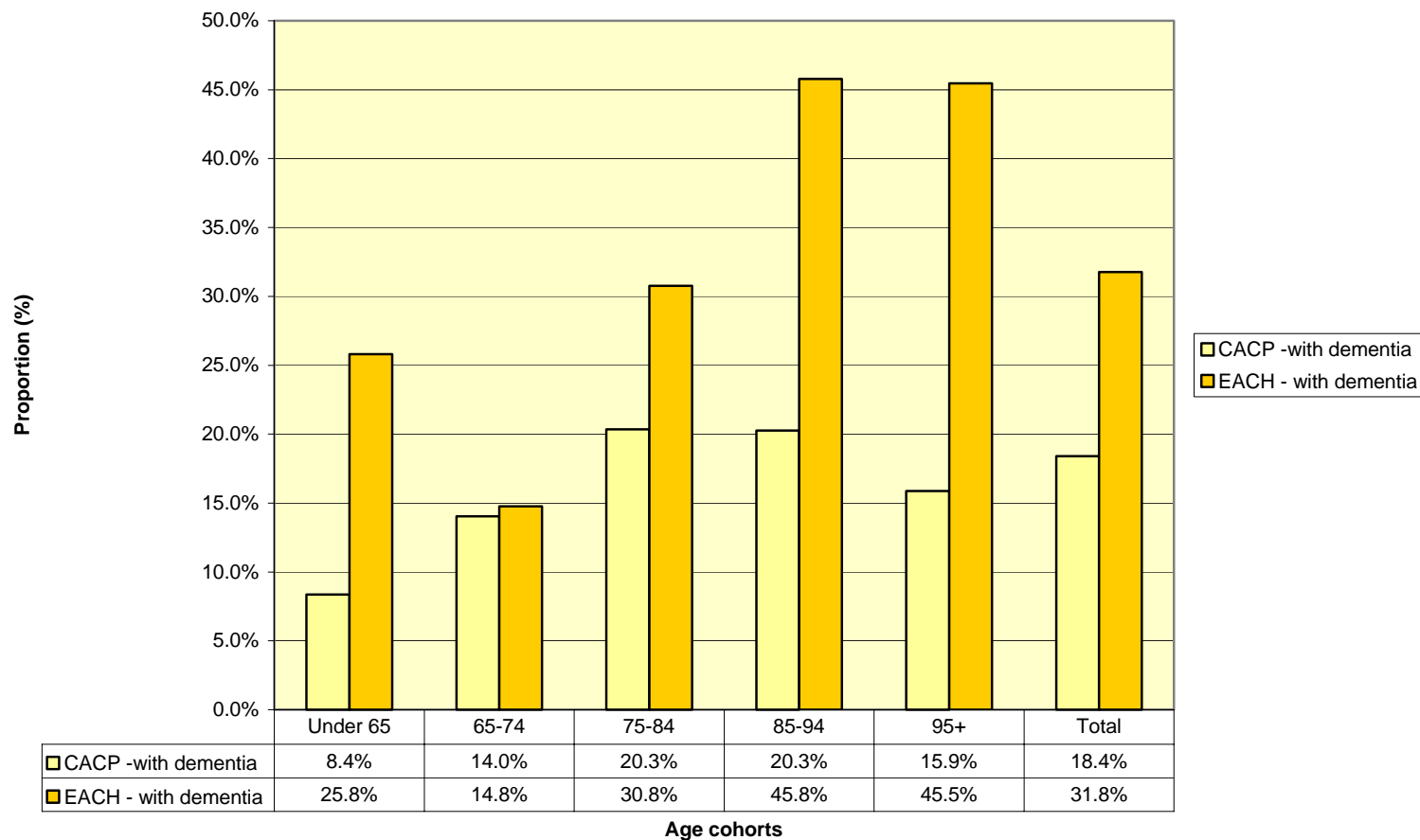
**Source:** AIHW (2004) *The impact of dementia on the health and aged care systems* - Data prepared by Policy & Analysis Unit, Aged Care Branch, Department of Human Services

**4. Community Aged Care Packages (CACP) recipients with and without dementia, by age, census week 2002**



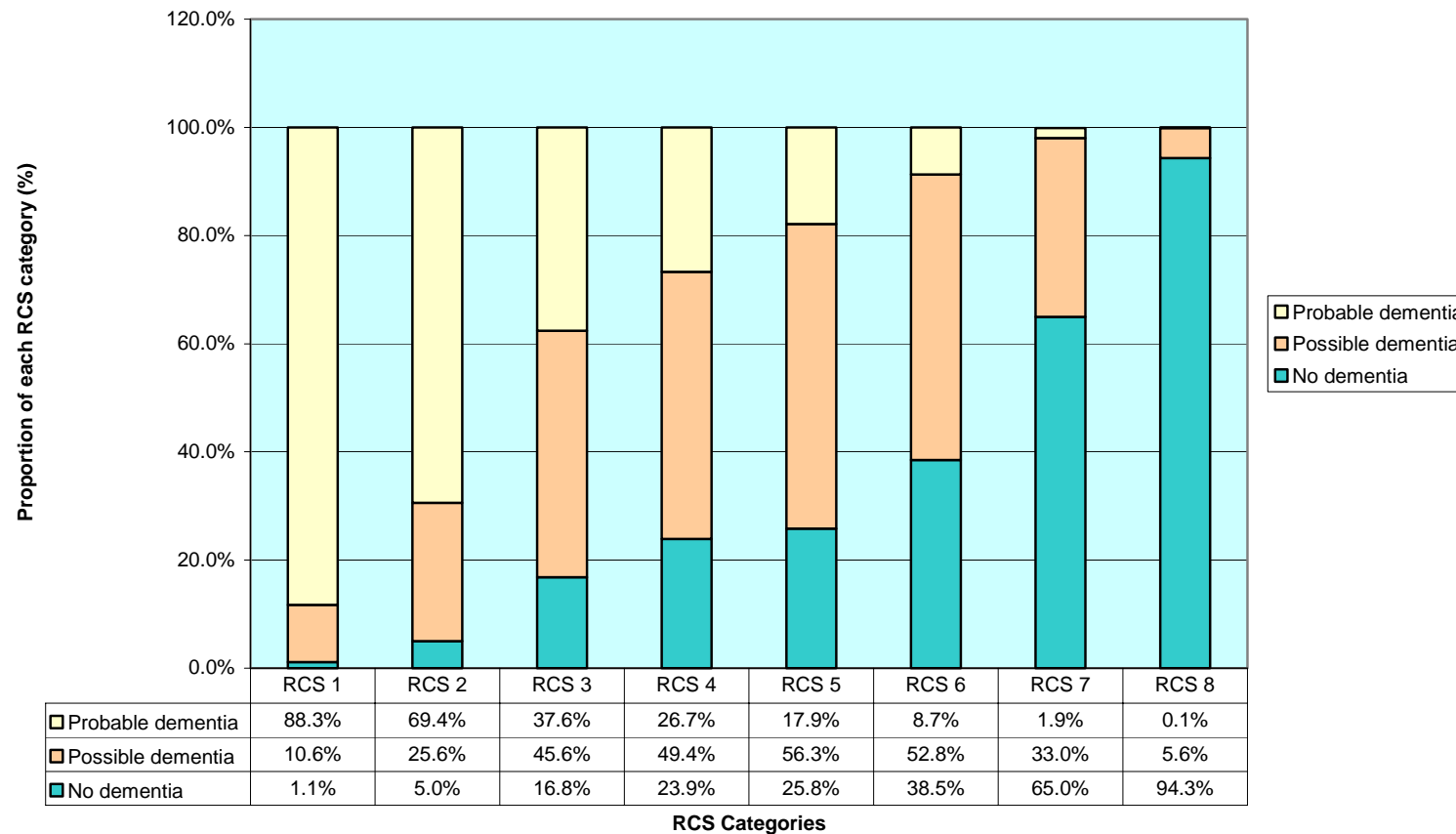
**Source:** AIHW (2004) *The impact of dementia on the health and aged care systems* - Data prepared by Policy & Analysis Unit, Aged Care Branch, Department of Human Services

**5. Community Aged Care Packages (CACP) & Extended Aged Care in the Home (EACH) recipients with and without dementia, by age, census week, 2002**



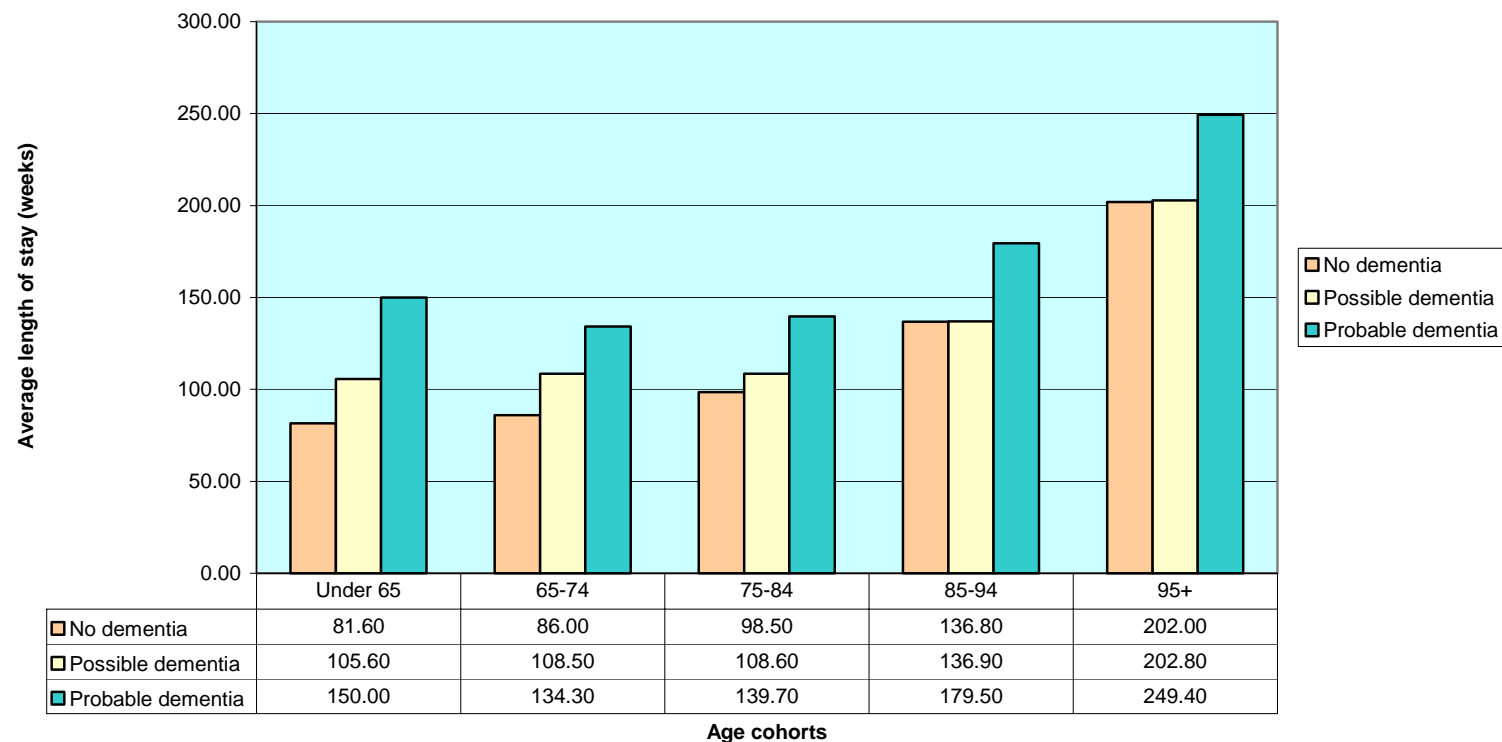
**Source:** AIHW (2004) *The impact of dementia on the health and aged care systems* - Data prepared by Policy & Analysis Unit, Aged Care Branch, Department of Human Services

**6. Residential Aged Care, permanent residents, Residential Classification Scale (RCS) and dementia status, 31 December 2002**



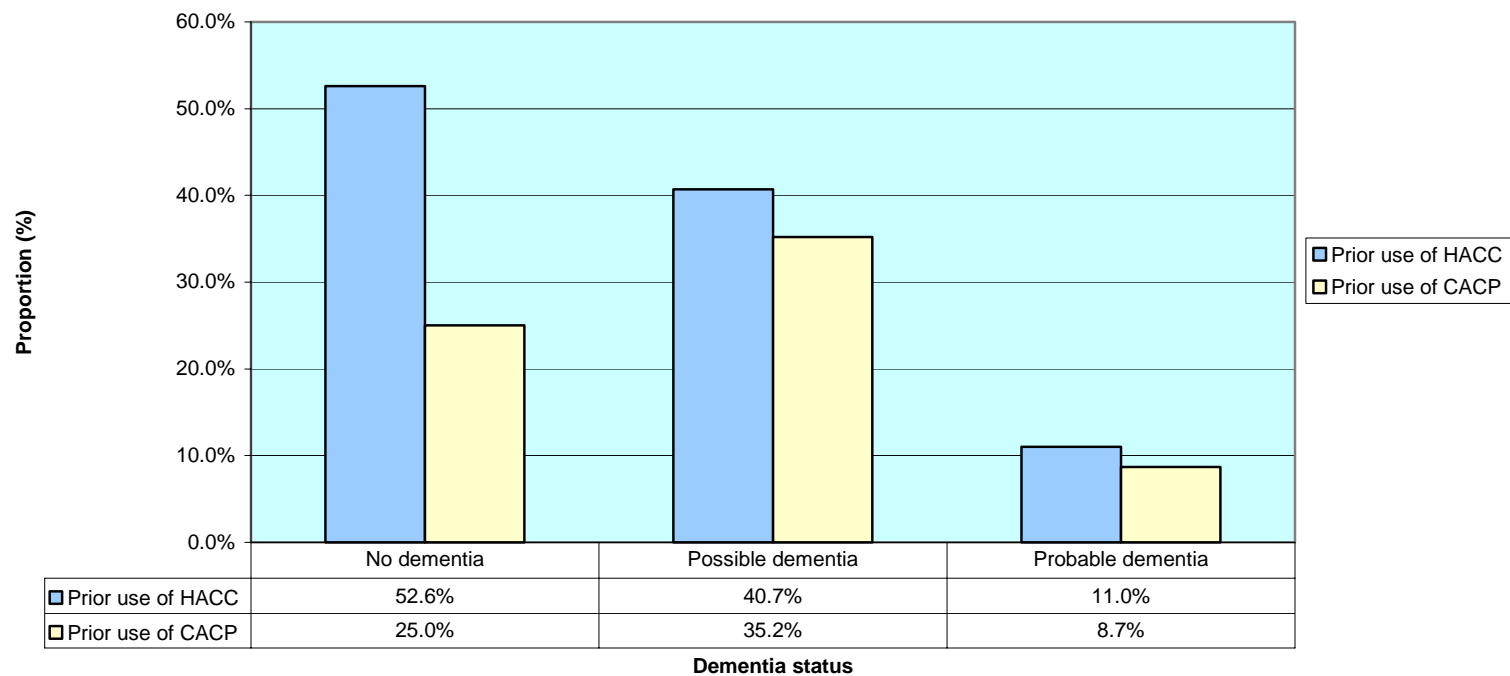
**Source:** AIHW (2004) *The impact of dementia on the health and aged care systems* - Data prepared by Policy & Analysis Unit, Aged Care Branch, Department of Human Services

**7. Residential Aged Care, Average Length of Stay (ALOS) by dementia status by age at separation, 2002**



**Source:** AIHW (2004) *The impact of dementia on the health and aged care systems* - Data prepared by Policy & Analysis Unit, Aged Care Branch, Department of Human Services

**8. Dementia status of users of HACC or CACP (1 July & 30 September 2002) prior to entry to permanent aged care (1 October 2002 & 31 December 2002), Australia**



**Source:** AIHW (2004) *The impact of dementia on the health and aged care systems* - Data prepared by Policy & Analysis Unit, Aged Care Branch, Department of Human Services

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