

Pathways to the Future,
2006 and Beyond

Dementia Framework for Victoria

pathways

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Aged Care Branch
Department of Human Services
April 2006

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Published by:
Aged Care Branch
Victorian Government Department of Human Services
Melbourne, Victoria, Australia

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Also published on <http://www.health.vic.gov.au/agedcare/>

Authorised by the Victorian Government, 50 Lonsdale Street, Melbourne

Acknowledgements

The many contributors to the development of this Directions Paper, including those who provided responses to the *Dementia Framework for Victoria, 2005 and Beyond Consultation Paper*, are gratefully acknowledged. The significant contributions of the Victorian Dementia Working and Reference Groups, representing key stakeholders in the development of dementia policy in Victoria, such as Alzheimer's Australia Vic (AAV), the Cognitive Dementia and Memory Services (CDAMS), and Carers Victoria are also acknowledged. Contributions are also acknowledged from Aged Care Branch programs and regional representatives, other Department of Human Services program areas, the Office of Senior Victorians, and the Office of the Public Advocate.

Foreword

The Victorian Government puts a high priority on quality, accessible health and community services, within a fairer society that reduces disadvantage and respects diversity. This means providing services that are responsive to the individual and diverse needs and preferences of Victorians, including those with dementia and their families and carers. It means welcoming and appreciating the ongoing role of people with dementia and their families and carers in our community.

Short and middle term demographic trends and predictions for Victoria's population suggest growing proportions and numbers of people with dementia, continuing for at least the next two decades. Many Victorians with dementia have families and carers, but single person households are increasingly a feature of Victorian communities, and there are also people with dementia living alone. Many people with dementia are in contact with neighbours and personal friends, work companions and various mainstream service providers, such as the local bank teller or pharmacist, who continue to interact with them.

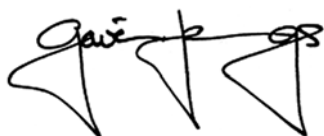
We need to value the ongoing contributions of people with dementia in our lives. Victorian services can support people with dementia to have productive, healthy, self-determining and enjoyable lives, whether living alone, with family and carers, or in supported accommodation services. Services and support should respond as needs of people with dementia change. Quality services and support are also needed to help maintain and enhance care relationships, so that carers and families can continue to provide care for as long as they choose to.

Each person with dementia has their own individual needs, as do their families and carers. Good practice in service delivery means that individual needs are met by innovative, flexible and responsive services. Services will increasingly be delivered in the home and at the primary care level. Together we can influence these services to be dementia friendly and support optimal quality of life, as we have started doing with hospitals, and residential and respite facilities.

A whole of community approach can: help us achieve the best possible understanding of dementia; deliver responsive services and provide support; and extend our knowledge into preventing, delaying the onset and progression of, and eventually moving towards a cure for dementia. A whole of community approach will engage:

- people with dementia
- their families and carers
- service and community organisations
- local, state and national governments
- the public, and
- the business, education and research sectors.

Together we can make a difference in the lives of people with dementia, their families and carers. I look forward to continue working with Victorians to meet the needs of those in our care, and enhance the quality of life of people who live with dementia and those who support them.



Gavin Jennings MLC
Minister for Aged Care

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1 Introduction

Background

This directions paper, and implementation plans to follow, provide information about the past achievements in Victoria in dementia policy and practice, Victoria's changing demographics, and the Victorian whole of government policy framework within which dementia directions for the State sit. Policy and practice strategies for 2006 and beyond that build upon the significant achievements arising from *Dementia Care and Support in Victoria 2000 and Beyond* are outlined, and provide clear priorities for the next five to ten years for government and service organisations.

The directions paper has been developed with the support and assistance of the Victorian Dementia Working Group¹, and following the extensive and positive feedback received in response to the *Dementia Framework for Victoria, 2005 and Beyond Consultation Paper*². Throughout the submissions received, many references were made to the current good practice being undertaken in dementia care and support within Victoria.

This directions paper, *Pathways to the Future, 2006 and Beyond - Dementia Framework for Victoria*, or *Pathways* considers what has been achieved in dementia policy and practice in Victoria, recognises changing demographics and findings of research over recent years, and builds on past achievements.

Pathways utilises the concept of the 'pathway of dementia'. The process of dementia begins almost invisibly and insidiously, slowly affecting a person and those surrounding and interacting with them, and culminates in the terminal decline of the person's central nervous system. Acknowledging these phases over time suggests that the 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.

Along the pathway, strategies to enhance client and carer experience, services and support focus on the following four priority areas:

- providing support to older people to live active and independent lives in their communities to the maximum extent possible
- facilitating high quality health and aged care services to support people with dementia and their families and carers
- encouraging creativity and innovation in flexible service delivery, and
- focusing on social connectedness, diversity and equity.

1. See Appendix 1: Victorian Dementia Working Group.

2. See Appendix 2: List of submissions to *Dementia Framework for Victoria, 2005 and Beyond Consultation Paper*.

Funding opportunities for the implementation plans to follow *Pathways* will continue to be sought to implement dementia strategies, including opportunities for Department of Human Services cross program activity. The Department of Human Services (the Department) will continue seeking to further progress implementation of dementia policy and practice in Victoria, by both enhancing existing partnerships and building new partnerships with external stakeholders.

Understanding the term 'dementia'

Before outlining the Victorian dementia policy and practice directions, and how best to build on past achievements, it is 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.'³

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)⁴. 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 pathway⁵. 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 transitions, individual autonomy continues to decline. Eventually, the effects of damage to the brain tissue are cumulative, disabling and terminal.

The dementia pathway is accepted by practitioners and specialists as a conceptual framework for following the progress of dementia⁶.

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

4. Appendix 3 provides details of forms of dementia.

5. Appendix 4 details stages of the pathway of dementia.

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

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.

Overview - dementia policy and practice 2006 and beyond

People with dementia are both inside and outside the service system, so support and care emanates from within communities and from service organisations. Responsibility for action around dementia rests with a range of organisations, including State Government, peak bodies, advocacy groups, researchers, service organisations, local governments, and the Commonwealth Government. It is important that partnerships continue to develop, 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 exploring opportunities for action, *Pathways* outlines strategies for dementia policy and practice. It is important to note that while the strategies build on past achievements, and are designed 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 unpaid carers occur 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 unpaid carers, this will reflect the development of a quality service generally⁷.

Strategies building on past achievements, and which aim to improve the experience of people with dementia and their families and unpaid carers, are related to:

- A. Healthy and active living, which may assist in preventing or reducing the risk of dementia.
- B. Early stages on the dementia pathway⁸.
- C. Middle stages on the dementia pathway⁹.
- D. Late stages on the dementia pathway¹⁰.

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

7. 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.

8. Research suggests that Victoria will experience a growing demand for early expert diagnosis, advice and support to and from individuals, families, unpaid carers and health organisations – 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 unpaid 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*.

9. 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.

10. Work by Brodaty and others suggests that in the late stages of dementia, training or intervention support for unpaid carers has positive impacts on both the unpaid carers and care recipients; for example, training of unpaid 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 unpaid carers. Training or intervention appears to improve unpaid carers' knowledge, decrease family burden, and improve coping skills.

themes can occur along the pathway of dementia to a greater or lesser extent, specific strategies are suggested to address them at various stages of the pathway. Responsibility for planning, implementing and evaluating these strategies rests with a range of different partners including: governments at the national, state and local levels; service organisations; peak bodies; individuals; and research bodies.

Table 1: Summary of strategies

Pathway stage	Strategies
A. Healthy and active living, which may assist in preventing or reducing the risk of dementia	<ul style="list-style-type: none"> • Promoting positive ageing and social connectedness • Early life planning • Meeting diverse needs such as those of Aboriginal and Torres Strait Islander (ATSI) communities, people who are homeless, people living in rural and remote areas, and people from culturally and linguistically diverse backgrounds
B. Early stages on the dementia pathway	<ul style="list-style-type: none"> • Promoting positive ageing, and social connectedness • Life planning • Education and information • Service development and enhancement • Support for people with dementia and their carers • Respite and residential accommodation • Meeting diverse needs
C. Middle stages on the dementia pathway	<ul style="list-style-type: none"> • Forward planning • Service development and enhancement • Support for people with dementia and their carers • Respite and residential accommodation • Meeting diverse needs
D. Late stages on the dementia pathway	<ul style="list-style-type: none"> • Transitions from living at home to residential care • Service development and enhancement • Support and counselling for families and carers • Respite and residential accommodation • Meeting diverse needs

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 unpaid carers, including flexible respite and counselling
- information and resource materials
- participation of people with dementia and their families and unpaid carers in decisions about diagnosis, treatment and care

- training and education for all people involved in the care of people with dementia, including families and unpaid carers, service organisation staff, and volunteers
- research on risk reduction, prevention, treatment and care practices
- education of the general public and responsiveness, including community awareness and de-stigmatisation, community support and social connectedness¹¹
- appropriate care and management in hospitals of older people with complex needs and of people with cognitive impairment¹², including reducing the use of physical or chemical patient restraints which increase the risk of adverse events¹³
- system interfaces/ design, including:
 - awareness of a whole of government approach
 - improved screening and assessment processes¹⁴
 - entry to a continuum of care system, which in the early stages offers an opportunity to build confidence in the system, and can reduce at the middle and late stages crisis management and premature admission to residential aged care
 - access to case managers to promote consistency of information, continuity of care and a smooth transition to residential care
 - fostering partnerships
 - implementation of collaborative models across all health sectors, including GPs
- development of best practice evidence based guidelines
- removing restrictions in the service system that can work against innovative practices, for example Commonwealth Government guidelines
- protection of rights and interests
- strategies for preventing elder abuse
- preventing behavioural and psychological symptoms of dementia – BPSD (described by health professionals as challenging behaviours)

11. 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 are recognised in 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 2006 and beyond aims to promote people with dementia and their unpaid carers remaining active and participating members of their communities and encouraging efforts to facilitate this, seeking support from the Department for Victorian Communities and the Primary Care Partnerships.

12. 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 2004–30 June 2005, there were 17,778 patients over 40 years of age admitted to public and private hospitals with a dementia diagnosis, as a principal or an additional diagnosis.

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

14. 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. It is acknowledged that screening tools should not be used to diagnose dementia, but without the assistance of screening instruments clinicians may commonly miss dementia in routine practice. Other screening instruments include the clock-drawing test, and the Alzheimer's disease Assessment Scale. Some tools have a dual role in incorporating cognitive screening instruments and diagnostic schedules. Other tools focus on information from families and unpaid carers.

- providing consistency and equity of services across Victoria, including to rural and remote regions, for example, support, education and training.

People have diverse needs to be addressed, with particular strategies required to support them and their families and unpaid carers. People who may find the service system not especially user friendly include:

- ATSI communities
- people who are homeless¹⁵
- other diverse needs groups such as people with Down syndrome and dementia; people with frontotemporal dementia; people with younger onset dementia¹⁶; and people with psychiatric conditions
- people living in rural and remote areas
- people from culturally and linguistically diverse (CALD) backgrounds¹⁷.

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

16. In June 2004, there were about 218 people aged less than 50 years in Victoria's residential aged care services. In September 2004 DHS commenced a strategic project to consider the service needs and options for younger people in residential aged care. The target group includes younger people with a disability aged less than 65 years, particularly focusing on those aged 50 years and less. Key objectives include developing more appropriate and sustainable long-term accommodation and support options for younger people with a disability through: improving service responses to those requiring the level of care provided in residential aged care services; creating opportunities for those seeking to move from residential aged care to more appropriate community options; and preventing inappropriate admissions. The work of the project is informing Victoria's participation in the Council of Australian Governments (COAG) Health Reform agenda.

17. 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.

2 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 families and unpaid carers
- improve access to services for people with dementia, their families and unpaid carers
- improve public awareness of dementia, and access to education and information resources about dementia
- take a partnership approach to identifying and developing appropriate responses to the needs of people with dementia, their families and unpaid carers.

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 organisations include the following.

Service system development

Different people with dementia and their families and unpaid 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 specifically to meet the needs of people with dementia and their families and unpaid 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 BPSD (described by health professionals as challenging behaviours), and a focus on improving care for older people in health services. Initiatives include:

- establishment of the Cognitive Dementia and Memory Services (CDAMS)
- review of the CDAMS, and increased recurrent funding for the service
- growth of the Aged Persons Mental Health Program
- following national initiatives, a 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 unpaid 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 families and unpaid carers

In addition to service development, there has been a growth in support services for people with dementia and their families and unpaid 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 unpaid 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 aims to purchase flexible support services to meet the individual and variable needs of families and unpaid 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 ATSI 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 unpaid carers throughout Victoria, and includes specific funding for one Dementia Care Support Worker in each region to provide one on one support to unpaid carers of people with dementia.

Education and training

Initiatives have been undertaken to train, educate and assist workers and organisations in a range of settings on dementia care and management, and unpaid carer inclusiveness. These include in-service training and accredited training, and the development of manuals or guidelines to assist workers and organisations in dementia friendly and unpaid carer inclusive practice. Initiatives include:

- education and training of community care workers, including a focus on dementia in training of HACC community care 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 settings¹⁸, culminating in the publication *Dementia care in hospitals: Key findings and ideas from the evaluation of four projects*, July 2005

18. These projects appear to reflect national directions for improving the care of older people across the hospital-aged care continuum. The Australian Health Ministers Advisory Council (AHMAC) Care of Older Australians Working Group released: *A guide for assessing older people in hospitals* in September 2004; and *Best practice approaches to minimise functional decline in the older person across the acute, sub-acute and residential aged care settings* in November 2004.

- manuals and kits on transition to residential aged care, including unpaid carer inclusive practice by service organisations
- funding to Alzheimer's Australia Vic (AAV) to undertake training in dementia care and understanding.

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 unpaid carers indicating the impact of dementia on their lives. Peak bodies such as 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 unpaid carers, organisations and workers, 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 AAV
- ongoing financial and other support for Dementia Awareness Week, which in 2005 became Dementia Awareness Month, and focused on the health promoting campaign **Mind your Mind**.

Appendix 5 summarises services in Victoria for people with dementia and their unpaid carers.

There has been progress in meeting the needs of people with dementia and their families and unpaid carers¹⁹. The future sees changes in the demographic makeup of the Victorian population, and further opportunities for improvements in dementia policy and practice.

19. 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.

3 Dementia and the changing demographics of Victoria

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 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 forecast 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)²⁰.

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 aged care and at home.

Diverse needs in Victoria

Victoria's population is diverse, including people of various:

- cultural and linguistic backgrounds
- socio-economic backgrounds
- locations
- physical and intellectual abilities
- household structures.

Services need to be able to meet the diverse needs of the Victorian population.

*Preparing for Victoria's Future – Challenges and Opportunities in an Ageing Population*²¹, suggests that ageing impacts will be most pronounced within culturally and linguistically diverse communities, and in regional Victoria. The paper says that:

- although Melbourne and Victoria will develop an older age profile over coming decades, Melbourne will remain younger on average than regional Victoria, largely due to an inflow of young people, especially those aged between 20–29 years old

20. Source www.dse.vic.gov.au/ See also Victorian Government Department of Human Services 2003. *Improving care for older people: a policy for Health Services*.

21. Victorian Government Submission to the Productivity Commission Research Study on the Economic Implications of an Ageing Australia, November 2004.

- many rural areas and small towns have a very high percentage of their population that are older, driven by emigration of young people and the 'ageing in place' of older age groups. Retirees and semi-retirees seeking a 'sea change' are also migrating to regional areas, putting pressure on most coastal areas and some inland regions
- regional Victoria already has an older age profile than Melbourne, with 31.7% of people aged 50 years or over, compared with 28% for Melbourne. Ageing is affecting regional Victoria before Melbourne, and in some parts of regional Victoria, the effects of a rapidly ageing population are already being felt
- single parent families, couples without children, and lone person households will increasingly become prevalent household types. Many single person households will be people separated from their partners, and older Victorians whose partner is deceased
- it is estimated that 20% of those aged 75-79 years have a profound or severe disability, compared with 10% aged 65-69 years
- Victoria has a relatively smaller population of older people of ATSI origin compared with other states
- the state has a higher population of people from other cultural and linguistic backgrounds. Older people from culturally and linguistically diverse backgrounds are growing at a faster rate than for other older Australians
- in Victoria, Melbourne has the most substantial increase in the CALD population. By 2011, 38% of Melbourne's older population, about 194,200 people, will be from culturally and linguistically diverse backgrounds, up from 29% in 1996.

Down syndrome is the most commonly occurring genetic condition. Worldwide, for every 600 to 700 babies born, one has Down syndrome. The average life expectancy of a person with Down syndrome is 55+, with some people living into their 80s. Despite the fact that almost everyone with Down syndrome develops the brain changes characteristic of Alzheimer's disease by around 40 years of age, the average age for behaviour changes is reported to be 54 years. However, some people with Down syndrome have lived into their 60s and 70s, with no evidence of the behaviours associated with Alzheimer's disease. Thus there is no inevitability about the onset of the disease, and studies suggest that not every person with Down syndrome will develop the clinical symptoms of Alzheimer's disease ²².

The Department's Disability Services Division indicates that of Victorians with an intellectual disability, including but not exclusively Down syndrome, who receive services, and are aged 41 and over:

- 2,065 people live in Shared Supported Accommodation
- 339 people are in Congregate Care
- 146 have Flexible Support Packages
- 203 receive HomeFirst services.

22.

http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Down_syndrome_and_Alzheimer's?OpenDocument

Demographics of dementia in Victoria

The changing demographics of the Victorian population are of importance for extending dementia policy and practice. Short to middle 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 2005 about 52,500 people had dementia, with this figure estimated to increase to approximately 83,600 by 2020.

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 about 36,300 in 2005 to an estimated 58,400 in 2020; it is predicted that the North and West Metropolitan Region will experience the most marked increase in the number of people with dementia, from about 12,500 in 2005 to an estimated 21,500 in 2020.

Regional Victoria has a higher incidence and prevalence of dementia than metropolitan Victoria, given the former's older populations. In rural and regional Victoria, the number of people with dementia is forecast to increase from about 16,300 in 2005 to an estimated 25,100 in 2020; of rural regions, Barwon South Western Region is predicted to have the greatest number of people with dementia, with about 4,400 people with dementia in 2005 increasing to an estimated 6,600 by 2020²³.

A more long term prediction is an increase in the number of Australians with dementia from about 204,800 in 2005 to an estimated 619,000 in 2040, and 2.7% of the population by mid-century²⁴. While about 204,800 Australians have a diagnosis of dementia, there are perhaps as many again in the early stages of dementia²⁵.

Whilst dementia is not exclusively experienced by older people²⁶, 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 dementia²⁷. Of those aged 85 years and over, the estimate increases to 22-24% of people²⁸.

The *Victorian Burden of Disease Study – Mortality and morbidity in 2001*²⁹ shows that in 2001, for females dementia was ranked third, and for males ranked eighth, as the cause of disease burden in disability adjusted life years (DALYs).

There are also various predictions of demographic change among unpaid carers, including unpaid carers of people with dementia³⁰.

23. Alzheimer's Australia Vic *Summary of Key Points - Dementia estimates and projections: Victoria and its regions*, Access Economics 2005.

24. Access Economics 2005. *Dementia estimates and projections: Australian States and Territories*.

25. Source www.alzheimers.org.au Australian Dementia Statistics.

26. In 2003, about 1,700 Australians under the age of 60 were living with dementia (Survey of Disability, Ageing and Carers released by the Australian Bureau of Statistics in 2004, quoted by Access Economics 2005).

27. Alzheimer's Australia Vic, 2001.

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

29. Victorian Government Department of Human Services 2005.

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 Data Set (MDS) (2003–04)
- the Community Aged Care Packages (CACP)³¹ Census (2002)
- the Extended Aged Care at Home (EACH)³² 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 people 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 those living in the community at the time of assessment, 27.9%³³ were diagnosed with dementia, a similar proportion to the subgroup assessed by ACAS and receiving HACC. This proportion was similar in metropolitan and rural areas. The presence of dementia increased the likelihood of a residential care recommendation, especially for high level care.

30. 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 Australia 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'.

31. 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 organisation, 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.

32. 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.

33. Comprised of ATSI people aged 50 years and over, and others aged 70 years and over.

50.6% of clients with dementia received a recommendation for residential care, compared with 38.3% of all clients living in the community. Further, 25.4% of clients with dementia received a high level care recommendation, compared to 16.3% of clients living in the community³⁴.

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 10,500 persons with dementia. To them can be added perhaps 1,500 on either CACP or EACH packages.

Dementia and Supported Residential Services (SRSs)

Of approximately 7,000 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 pathway³⁵.

Dementia and residential aged care

The then Commonwealth Department of Health and Family Services³⁶ 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.

34. Aged Care Assessment Program Minimum Data Set Annual Report, Victoria, 2003-2004.

35. Source: Supported Residential Services Unit, Aged Care Branch, Rural & Regional Health & Aged Care Services, Department of Human Services, September 2005.

36. 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.

The report also estimated the proportion of residents rated with 'challenging behaviour'. Such behaviours may be challenging to workers 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
- 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 unpaid carers, such as the Victorian Cognitive Dementia and Memory Services). 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)³⁷.

While there was an estimated \$6.6 billion cost to Australia of dementia in 2002, more long term predictions include an increase in dementia costs from almost 1% of GDP in 2002 to more than 3% by 2050³⁸.

For additional data refer to the document *Dementia Framework for Victoria, 2005 and Beyond Consultation Paper*, which 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 systems*.

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

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

4 Future action in dementia policy and practice

At the state level

Victoria's whole of Government policy framework *A Vision for Victoria to 2010 and beyond - 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 ATSI and non-ATSI Victorians
- planning for the needs of our changing population at all stages of life.

Key strategic issues identified in GVT for Victoria are 'High quality, accessible health and community services', and 'A fairer society that reduces disadvantage and respects diversity'. GVT states that it is important that Victorians of all ages and abilities are assisted to stay healthy and active. With population ageing, Victoria needs to make sure that health and community services can meet the needs of senior Victorians; ATSI and poorer Victorians have poorer health than others. GVT suggests that long term improvements in the health of Victorians can be measured by how long we expect to live, and the quality of life during those years.

*Preparing for Victoria's Future – Challenges and Opportunities in an Ageing Population*³⁹ suggests that all Australian Governments work together on:

- a national program of health promotion,
- prevention and early intervention strategies to tackle the growth in chronic diseases such as dementia, and
- an integrated national system of primary and community health care, shifting the balance of care from hospitals to community based settings, to manage future pressures on health costs and slow the growth of age related chronic diseases.

Pathways builds on past achievements to better meet the needs of Victorians with dementia, and their families and unpaid carers, and reflects the directions and strategic issues of GVT and other Victorian Government directions. *Pathways* seeks 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 unpaid 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.

39. Victorian Government Submission to the Productivity Commission Research Study on the Economic Implications of an Ageing Australia, November 2004.

Considering achievements to date on dementia policy and practice in Victoria, Victoria's changing demographics, and whole of government policy directions, four priority areas provide the framework for the development of the strategies across the dementia pathway.

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, physical activity, intellectual stimulation and social connectedness etc, on delaying the onset and progression of or preventing certain dementias. There is low awareness of the causes of, and ability to delay onset of or prevent, certain dementias.
- Facilitate education of the general public 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)⁴⁰, and in supporting people with dementia and their families and unpaid carers.

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

- Incorporate dementia care and management into hospital care practice⁴¹.
- Increase the awareness of service organisations 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 behavioural and psychological symptoms of dementia - BPSD (described by health professionals as challenging behaviours), which may be challenging to workers and other residents in residential aged 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 aged care systems.
- Promote evidence based programs, and continuous improvement.

40. 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*).

41. 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 funded four projects in the education and training of all workers in the hospital setting in the care and management of patients with dementia, and an independent evaluation of the projects. This work has resulted in the DHS publication *Dementia care in hospitals – Key findings and ideas from the evaluation of four projects*.

Focus on social connectedness, diversity and equity

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

At the national level

The Commonwealth Government invests more than \$2.6 billion per year in dementia care, research and support. Through the Australian Research Council and National Health and Medical Research Council, the Commonwealth funds dementia research covering medical, health, and behavioural sciences, and social services. The Commonwealth introduced National Research Priorities in 2002 through the Department of Education, Science and Training; the issue of dementia is being addressed under the health priority 'Promoting and Maintaining Good Health'.

From 2005–2010, the Commonwealth Government's *Helping Australians with dementia, and their carers – making dementia a National Health Priority* will provide \$320.6 million, comprising:

- \$70.5 million to:
 - draw together dementia research and make it more accessible, help research institutes work together, and explore new dementia care and treatment options
 - support the primary health sector, including GPs in diagnosing and caring for people with dementia, create dementia and memory community centres⁴², and set up dementia study units
 - encourage prevention and early intervention for people at risk of dementia including publicising the best ways to help prevent or delay dementia through healthy lifestyles, and providing information and support for people with dementia, and their families and unpaid carers
- \$225.1 million for an additional 2,000 Extended Aged Care in the Home (EACH) packages specifically targeted to people with dementia and complex care needs
- \$25 million for dementia specific training for up to 9,000 residential aged care workers, and up to 7,000 people in the community, such as police, emergency services, and transport workers, who may come into contact with people with dementia.

42. The Commonwealth Government's Dementia and Memory Community Centres, to be run in each state and territory by Alzheimer's Australia, were intended to provide on-line memory testing, drop-in centres, day workshops and web-based health information, one to one counselling, support groups and education, for people with dementia and their families and unpaid carers. The Dementia and Memory Community Centres are distinct from the 15 Cognitive Dementia and Memory Services (CDAMS) in Victoria, which provide specialist multidisciplinary diagnostic, referral and educational services for people experiencing memory loss, or changes to their thinking, and for those who care for them. A number of the 15 CDAMS services across Victoria support outreach/satellite services, particularly in rural Victoria.

A trial is currently underway, funded by the Commonwealth Government, to validate the RUDAS tool⁴³, a culturally sensitive screening tool for dementia developed for people of CALD backgrounds⁴⁴.

In January 2005, Australian Health Ministers jointly agreed to the development of a national framework for action on dementia. The States and Territories, together with the Commonwealth Government, are developing a *National Framework for Action on Dementia 2006–2010*, anticipated for release by the Australian Health Ministers Conference (AHMC) in 2006. Appendix 6 lists the proposed strategies to be undertaken by the State, Territory and Commonwealth Governments in the draft *National Framework for Action on Dementia 2006–2010*, which are particularly relevant to the identified needs of Victorians with dementia, and their families and unpaid carers.

Pathways is helping to inform, and is informed by, the development of these national policy directions, and the planning and implementation of strategies across jurisdictional boundaries.

Within these Victorian and national environments, the following section outlines strategies for future action to address opportunities for change described above.

43. 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.

44. There is no validated tool to assess cognition in older ATSI Australians. Recent research by Dr Dina LoGiudice et al on 70 ATSI people aged over 45 years, 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 ATSI 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.

5 Strategies 2006 and beyond

Pathways to the Future, 2006 and Beyond - Dementia Framework for Victoria, focuses on four areas for action:

- A. Healthy and active living, which may assist in preventing, or reducing the risk of, dementia.
- B. Early stages on the dementia pathway.
- C. Middle stages on the dementia pathway.
- D. Late stages on the dementia pathway.

These areas are considered under the following headings:

- **Introduction**

Explores features of healthy and active living, or the early, middle or late stage of dementia.

- **Issues**

Identifies issues for people with dementia and their families and carers, service organisations, and governments. Responsibility for these issues lies with a range of organisations, including different service organisations and different government departments and programs.

- **Desired outcome**

Articulates the optimal desired outcomes for Victorians, given the issues identified.

- **Strategies**

Provides a range of strategies for the next five to ten years, aiming to address the issues raised and reach the desired outcomes for Victorians. Responsibility for implementing strategies rests with a number of organisations and individuals, including governments at the national, state and local levels; service and community organisations; the business and education sectors; peak bodies; individuals; and research bodies. The strategies include documentation and promulgation of good practice, and identification and piloting of innovative approaches for future service delivery.

Priorities within the strategies will be identified with actions in forthcoming implementation plans. Funding opportunities for the implementation plans to follow *Pathways* will continue to be sought to implement dementia strategies, including opportunities for departmental cross program activity. The Department will continue seeking to further progress implementation of dementia policy and practice in Victoria, by both enhancing existing partnerships and building new partnerships with external stakeholders.

A Healthy and active living, which may assist in preventing or reducing the risk of dementia

Introduction

It is expected that the evidence base on how to reduce the risk of dementia will strengthen in the next few years⁴⁵. In the future, as more is learned about dementia, minimising or reducing its debilitating effects might be achieved in various ways:

- prevention per se, so that 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 five month delay in onset of Alzheimer's disease is predicted to reduce new cases of Alzheimer's disease by 5% each year, resulting in an estimated 3.5% fewer cases by 2020 (4,583 people Australia wide). A five year delay in onset of Alzheimer's disease is predicted to reduce new cases by 50% each year, resulting in an estimated 35.2% fewer cases by 2020 (46,568 people)⁴⁶. Such reductions in the onset of Alzheimer's disease would have a major effect on quality of life of many people, and their families and potential unpaid carers. Any reduction in dementia is positive. Raising awareness of the general public 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 potential risk reduction measures.
3. Promotion of potential risk reduction strategies needs to avoid apportioning blame to people with dementia, and resulting in a sense of guilt for families and carers.
4. People have diverse needs, with particular strategies required to support them and their families and unpaid carers. For example, prevention strategies need to be seen in a cultural context, and be culturally sensitive.
5. 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 conditions⁴⁷.

45. 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 has been recently reviewed. See Lautenschlager N T et al 2003, *International Psychogeriatrics*. Vol 15, No 2 p 111, and Woodward 2005 *Alzheimer's Australia Position Paper* 6.

46. Access Economics Pty Ltd, 2004.

47. 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. Another issue is that enduring powers of attorney are not recognised across state and territory boundaries.

Desired outcome

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

Strategies

Promoting positive ageing, and social connectedness

- Support and facilitate awareness raising activities targeting the general public on what dementia is, and risk reduction for the different types of dementia by various means, including by partnering with other relevant organisations. Life long lifestyle messages, around 'healthy body and healthy heart make for a healthy mind', include:
 - quitting smoking
 - reducing high blood pressure
 - reducing high cholesterol
 - maintaining mental and physical activity
 - having a healthy diet
 - maintaining an appropriate weight⁴⁸.
- Support organisations to implement programs, including targeting recent retirees to address the risk factors listed above, and continue to promote work on positive ageing strategies and social connectedness.
- Encourage partnership activities between organisations developing awareness programs with similar messages on risk reduction of chronic diseases.
- Use appropriate seniors web sites such as <http://www.seniors.vic.gov.au> to promote regional and statewide initiatives around education of the general public.
- Seek to encourage options for travel and mobility such as the Transport Connections Program.
- Encourage people, in particular those who are younger and at risk, to have annual health checks.

Early life planning

- Support the work of the Public Advocate to increase awareness in the general public and organisations about:
 - legislative changes on enduring powers of attorney and guardianship
 - benefits of early life planning for the future, including taking out powers of attorney⁴⁹

48. Woodward (2005) recommends a range of lifestyle strategies to reduce the risk of developing dementia, including: regular blood pressure checks; protection against head injury; intellectual stimulation; engagement in social/ leisure activities; avoidance of intense electromagnetic radiation; adequate intake of Vitamin E; healthy eating and avoiding too much fat; adequate B12 and folate intake; light to moderate drinking (not applicable to non-drinkers); being a non smoker; keeping physically active; and sleeping well.

49. 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.

- organising advance care directives, also known as Living Wills, or refusal of treatment certificates⁵⁰.

Meeting diverse needs

- Support and facilitate awareness raising activities on life long lifestyle messages, including for ATSI and CALD communities, using established community networks and media.

Community education and support, and Pearl

Pearl is a widow in her late 70s. She has mild dementia, lives alone, has no relatives in the state, and was referred to Do Care following hospitalisation for depression.

Pearl was rejected by others in her Senior Citizens Club (she had been an office bearer) and gave up her driving licence. She stopped visiting her closest friend, or going shopping because of embarrassment when she forgot what she wanted. Pearl's feeling of rejection and her memory problems greatly reduced her confidence. She said she felt lonely but felt staying at home was the 'safest' option.

Following regular visits from a visitor from Do Care, Pearl's trust has been built up and she can now, with her companion, visit her friend, and go to the library, and she has started visiting an armchair travel group. She is feeling more confident and is no longer taking anti-depressants.

A community education session on memory change was organised for the Senior Citizens Club, with pamphlets on the early signs of dementia, how families and friends can help people with dementia, and what help there is for families and carers. Follow up talks are being organised on positive ageing, and forward planning.

50. An advance directive does not appoint a substitute decision maker. It is normally a document in which a person specifies in advance what medical treatment they would like to receive if they become unable to make, or communicate, such decisions. An advance directive also allows a person to tell their doctor what treatment they do not want in a particular situation (www.alzheimers.org.au/upload/Legal%20information%20paper1.doc).

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 unpaid 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 general public, people are generally uncertain about whether or how to act 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. Service organisations can find it challenging to acknowledge such feelings, and to use a positive approach to assist people through them.

In the early stages on the dementia pathway, it is important to be able to differentiate accurately between early dementia, and other conditions that may be taken for dementia. For example, changes in individuals can occur through 'normal' ageing⁵¹, some people may develop a Mild Cognitive Impairment (MCI)⁵², others may have delirium or depression⁵³, and some may have dementia.

For people diagnosed with dementia in the early stages of the dementia pathway, differentiating the dementia is important, as it may have implications for management and treatment (including the need to exclude reversible causes)⁵⁴.

Knowledge of the progressive nature of dementia 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 unpaid carer support.

51. '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.

52. 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).

53. Appendix 3 provides details of depression and delirium, which can mimic dementia.

54. Appendix 3 lists forms of dementia and their features.

Most people with early stages of dementia continue to live active and productive lives in their own homes. A small number of people in the early stages on the dementia pathway live in Supported Residential Services (SRS) accommodation⁵⁵.

Appendix 4 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 unpaid carers. These issues are even more marked in culturally and linguistically diverse communities.
2. GPs and other primary health care services are not all able to recognize possible dementia (or may make a misdiagnosis of dementia), and therefore may hinder early diagnosis, appropriate early planning, and support for people with dementia and their families and unpaid carers.
3. Other service organisations are not all alert to the possibility of cognitive decline, and so may not provide appropriate support and referrals.
4. Commonwealth Government policies, programs, and initiatives such as the Community Care Review, and ACAS initiatives in the Commonwealth Government budget, impact on service delivery, for example on levels of funding, program guidelines, and service system development.
5. People have diverse needs, with particular strategies required to support them and their families and unpaid carers.

Desired outcome

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

Strategies

Promoting positive ageing, and social connectedness

- Continue to promote work on healthy and active living, positive ageing strategies, social connectedness and information about dementia through websites.

55. 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.

Early life planning

- Support the work of the Public Advocate to increase awareness in the general public and organisations about:
 - legislative changes in relation to enduring powers of attorney and guardianship
 - benefits of early life planning for the future, including taking out powers of attorney⁵⁶
 - organising advance care directives, also known as Living Wills, or refusal of treatment certificates.

Education and information

- Promote awareness raising and education about dementia, including to secondary schools and tertiary institutions, 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.
- Explore opportunities to review existing education programs. Facilitate the development of comprehensive education packages that include dementia specific information (in relation to all stages and treatment options) for staff across all health sectors.
- Promote the importance of including dementia specific and public health information in Vocational Education Training (VET) and university courses at all levels.
- Promote links between specialist dementia information services and other information services.

Service development and enhancement

These strategies are consistent with directions in a range of services, including Victoria's Community Health Services policy⁵⁷.

- Identify and promote the best ways to assist people with dementia, and their families and unpaid carers to navigate the community care system.
- Identify entry points in acute care that are sensitive to people with dementia and the needs of their families and unpaid carers, and promote dementia care standards and quality standards in acute care.

56. 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.

57. 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.

- Promote and extend access to Cognitive Dementia and Memory Service (CDAMS) services⁵⁸.
- Promote the development of best practice evidence based guidelines to address assessment, diagnosis, treatment, support options and legal issues.
- Support the out-posting of community services professionals, for example AAV counsellors, or district/community nurses, with expertise in dementia, to support GPs in their work with people with dementia and carers.
- Facilitate the use of practice nurses in GPs, or a case manager in GPs, for example to boost community capacity to keep people out of hospital. Existing models using practice nurses could be extended to other disciplines with expertise in dementia, to provide holistic care through general practices.
- Promote and where appropriate extend other services such as ACAS – seek to increase ACAS skill and capacity to undertake assessments where there are memory or orientation issues, and to provide advice to service organisations as part of care planning and service co-ordination, managing behaviours, etc. Promote regular training and provision of information on the latest findings on dementia care and management⁵⁹.
- Foster partnerships (for example with Carers Respite Centres, GPs, CDAMS and ACAS) and develop collaborative models to improve access to services across all health sectors, including community, acute, sub-acute and residential care^{60 61}.
- Encourage use of Medicare Enhanced Primary Care (EPC) items, for example Annual Health Assessments for people over 75 years, Allied Health and home medication reviews.

58. 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 15 CDAMS services provide an accessible, multidisciplinary, specialist service for early diagnosis, advice, support and referral for people with cognitive difficulties. The CDAMS service 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 unpaid 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 unpaid carers, and maximize preventive treatment effects for those with dementia. They aim to assist families and unpaid carers to conceptualise and articulate their concerns, and access education and other supports.

59. 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.

60. Recommendation 7 of the 2003 CDAMS review refers to the need for collaborative relationships between CDAMS and primary and community care organisations, 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.

61. 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, could be used in GP surgeries, enabling early dementia screening.

- Review the guide to deal with elder abuse, including in relation to dementia.

Support for people with dementia and their unpaid carers

- Promote the provision of early support to people with dementia, and their families and unpaid carers. Include case management, social programs, links with other families and carers through the progression of dementia.
- Promote quality of life of people with dementia, and their families and unpaid carers through timely access to appropriate services and assistance⁶², by promoting appropriate policy and practice in HACC, and support to HACC workers.
- Promote awareness about changing driving capacity, and seek to encourage options for travel and mobility such as the Transport Connections Program.

Community based respite and residential accommodation

- Encourage the development of early responsive respite that meets needs, for example providing low key flexible and responsive respite and programs early, rather than in crisis situations alone, to address social connectedness, and providing where appropriate culture and language specific respite.
- Promote appropriate policy and practice in Supported Residential Services (SRSs) for residents with a diagnosis of dementia and their families, and other health care organisations. Seek opportunities to provide support to SRS operators, for example through the provision of training opportunities, advice and written resources.
- Promote awareness of the availability and benefits of respite to those with dementia and their unpaid carers, including assisting to reduce carer stress and burnout, facilitating regular monitoring, and preparing the client and carer regarding the future possibility of transferring to residential aged care facilities.

Meeting diverse needs

- Identify specific barriers for people of diverse needs in accessing care and support.
- Support the development of appropriate service models to meet the needs of diverse groups.
- Support the development of ATSI specific strategies informed by the Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004–2009 (Australian Health Ministers Advisory Council).
- Promote the availability of information on treatments, support and services⁶³, accommodation, screening, assessment and self-assessment tools, respite,

62. In an address to the Victorian Dementia Reference Group in November 2004, the Public Advocate referred to the need for policies and practices to avoid the unintended consequences of overriding client rights, and client opportunities to maximise their autonomy and enjoyment of life.

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

and promoting healthy lifestyle models, in community languages on the web, in print and in other formats suitable for community groups including people from culturally and linguistically diverse backgrounds (CALD).

- Incorporate in training programs ways to identify diverse needs, appropriate interventions and available specialised supports, to respond to client and carer needs.

What does your organisation do?

Alzheimer's Australia Vic (AAV) provides an extensive range of information sessions, education and support programs for people in the early stages of the dementia pathway and their families and unpaid carers. This includes the Living with Memory Loss program which focuses on the person with dementia and the further support offered in the Memory Lane Café. Dementia information sessions are also provided for families and unpaid carers, including for people from CALD backgrounds. Other major services include the Dementia Helpline, individual counselling (phone and home) and Telephone Outreach for people in rural and remote locations. Support groups throughout Victoria are resourced and supported by AAV. The organisation also delivers major awareness campaigns, such as Dementia Awareness Month which in 2005, focused on the seven aspects of **Mind your Mind** - looking after your: body, diet, brain, health checks, social life, head, and habits, which may reduce the risk of developing dementia.

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 symptoms of dementia (BPSD); these people may need highly specialized services, and workers 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 unpaid 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 workers.

Appendix 4 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 unpaid 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 HACC services through to Community Aged Care Packages (CACPs). Waiting for support can increase the pressure on unpaid 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 unpaid carers can lack co-ordination, and establishing services requires dealing with a number of health professionals and support workers.
4. The service system both is, and is perceived by many as, complex.
5. Respite services are not always appropriate and flexible enough to meet needs.
6. People with dementia may exhibit behavioural and psychological symptoms of dementia – BPSD, described by health professionals as challenging behaviours.

7. Providing timely and appropriate access to new information can be challenging for stakeholders in the service system.
8. People have diverse needs, with particular strategies required to support them and their families and unpaid carers.

Desired outcome

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

Strategies

Life planning

- Support the work of the Public Advocate to increase awareness in the general public and organisations about the benefits of planning for the future, including organising advance care directives, also known as Living Wills, or refusal of treatment certificates, and taking out powers of attorney.

Service development and enhancement

- Identify entry points in acute care that are sensitive to people with dementia and the needs of their families and unpaid carers, and promote dementia care standards and quality standards in acute care.
- Identify and promote the best ways to assist people with dementia, and their families and unpaid carers to navigate the community care system.
- Focus on moving people into a continuum of quality of care, including flexible respite, and a coordinated and simplified service system. Promote a reduction in program boundaries, and care tasks delivered by one community care worker or a small regular group of community care workers where possible, rather than differing community care workers⁶⁴.
- Encourage service organisations to utilise waiting lists for CACPs⁶⁵ and other programs, to access people in the middle 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. The current move towards centralised waiting lists, for example based on regional departmental boundaries, will assist this process.
- Encourage professional development and training across all health sectors in behavioural and psychological symptoms of dementia – BPSD, described by health professionals as challenging behaviours.

64. The Commonwealth Government in August 2004 released its review of community care, *A New Strategy for Community Care – The Way Forward*. It was hoped the review could: facilitate case management support for individuals with dementia and their unpaid 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 unpaid carers in the review outcomes.

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

- Promote a holistic approach, including high quality nutrition, hydration, dental health care practices, and pain management for people with dementia⁶⁶.
- Seek to encourage options for travel and mobility such as the Transport Connections Program.
- Review the guide to deal with elder abuse, including in relation to dementia.

Support for people with dementia and their unpaid carers

- Encourage on-going monitoring of the needs of people with dementia and their families and unpaid carers across all sectors of the health care system, for example CACPs and programs such as the Support for Carers Program which provides information, support, day activities, and respite.

Community based respite and residential accommodation

- Promote appropriate policy and practice in SRSs for residents with a diagnosis of dementia and their families, and other health care organisations. Seek opportunities to provide support to SRS operators, for example through the provision of training opportunities, advice and written resources⁶⁷.
- Promote awareness of the availability and benefits of respite to those with dementia and their unpaid carers, including assisting to reduce carer stress and burnout, facilitating regular monitoring, and preparing the client and carer regarding the future possibility of transferring to residential aged care facilities.

Meeting diverse needs

- Identify specific barriers for people of diverse needs in accessing care and support.
- Support the development of appropriate service models to meet the needs of diverse groups.
- Support the development of ATSI specific strategies informed by the Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004–2009 (Australian Health Ministers Advisory Council).
- Encourage the provision of culturally appropriate information and support to people with dementia and their families and unpaid carers, in community languages.
- Encourage the use of appropriately skilled and experienced bilingual bicultural people and bilingual personal carers to assist in the process of accessing appropriate care, and using appropriate respite.

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

67. 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).

Supporting care relationships

Jim would spend most of the day in his pyjamas, and his partner, Chris, had major problems encouraging Jim to shower and shave. Chris became increasingly tired, anxious and stressed, as Jim's behaviour continued to change. Both Chris and Jim's lives transformed, when Jim was introduced to a Men's Group. Every week the Men's Group met, and participated in various stimulating and meaningful activities. The activities, which were outings based, were planned with, and reflected the interests and skills of, the men. Activities included day trips to places of interest, community walks, exercise and swimming classes, and attendances at various events. Jim became highly motivated to attend the Men's Group, forming friendships with some of the other participants.

Jim now gets himself out of bed, dressed and shaved in the morning, alert and interested, ready for the bus to the Men's Group. Chris has been able to have a regular break from caring, and time out, resulting in better physical and emotional health. The care relationship has also improved, with more communication and interaction between Jim and Chris. Chris also feels that now, in-home respite and residential respite will be more acceptable to Jim. And both Jim and Chris are currently accessing valuable services and support from other organisations.

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 late stages of dementia, their 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 late stages of dementia will require such high levels of care that their needs may best be met in residential aged care facilities⁶⁸.

Some people will exhibit severe behavioural and psychological symptoms of dementia (BPSD - described by health professionals as challenging behaviours) early in this stage of dementia; these people may need highly specialized services, and workers need to be highly skilled in working effectively with them. BPSD may diminish as a person's condition deteriorates.

Special issues emerge at end of life for people with dementia, and their families and unpaid carers, including palliative care, and grieving.

Appendix 4 provides more detail of this stage on the pathway of dementia.

Issues

1. Transitions from living at home to residential aged care can be difficult and challenging for people with dementia, and their families and unpaid carers.
2. People with dementia may exhibit BPSD, described by health professionals as challenging behaviours.
3. Families and unpaid carers may increasingly grieve the loss of the person they know.
4. Residential aged care may be affected by systemic issues such as: untrained workers; 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 BPSD⁶⁹; inadequate staffing and staff mix to meet the needs of people with BPSD, including psychosocial interventions; residential aged care environments not planned to meet the needs of people with dementia.

68. 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). It is unlikely that people in the late 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 workers.

69. 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 Commonwealth Government announced in the 2004 budget that it would implement a new funding system for residential aged care in response to recommendations from the Hogan Review. The new system, expected to be introduced in late 2006, will have fewer categories than the current Resident Classification Scale, and will include two new supplements. The new supplements are intended to better target available funding towards the highest care needs, in particular residents

5. People with dementia and their families and unpaid carers face end of life.
6. People have diverse needs, with particular strategies required to support them and their families and unpaid carers. For example, in the late stage of the dementia pathway, as some people return to their primary language, communication in the primary language, and culturally sensitive care and services, are vital.

Desired outcome

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

Strategies

Transitions from living at home to residential aged care

- Develop protocols and practices, training of service provider staff, and support for carers at critical intervention points in service delivery, such as transition from hospital back to home or to residential care, transition from home to respite or residential care, and making appropriate referrals.

Service development and enhancement

- Identify entry points in acute care that are sensitive to people with dementia and the needs of their families and unpaid carers, and promote dementia care standards and quality standards in acute care.
- Work across departmental program areas to enhance training for various groups of workers in metropolitan and rural areas, including mental health, disability services, palliative care, GPs, acute and sub-acute, community care for people living independently in the community, and residential aged care services, encouraging appropriate, positive, responsive and timely care.
- Promote a holistic approach, including pain management and dental health⁷⁰, to BPSD, described by health professionals as challenging behaviours, and the availability of specialized care, usually provided by Aged Persons Mental Health Services, for people with severe BPSD.
- Encourage reduction in the use of physical or chemical patient restraints, which increases the risk of adverse events, in hospitals, sub-acute care, respite care, and residential aged care facilities.

with dementia and challenging behaviours, and residents with complex health and care needs, including palliative care. The Commonwealth Government has made dementia a national health priority, with funding over five years for 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 workers.

70. For example, educate unpaid carers and residential aged care workers 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.

- Continue to work with the Department's Continuing Care and Clinical Service Development Program and others to maintain awareness of the needs of people with dementia and their families and unpaid 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.
- Review the guide to deal with elder abuse, including in relation to dementia.

Support and counselling for families and unpaid carers

- Promote communication with clients, their families and organisations on planning of services, counselling and support, and end of life issues, including grief counselling for what is lost.
- Promote availability of information about available supports, advocacy services, and complaints processes, including the Health Services Commissioner, and post grievance support and counselling.

Community based respite and residential accommodation

- Promote appropriate policy and practice in Supported Residential Services (SRSs) for residents with a diagnosis of dementia and their families, and other health care organisations. 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.
- Research literature and practice on appropriate respite and residential aged 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, in hard copy and web based for relevant stakeholders, and seek to establish a demonstration model/s⁷¹. Examine the transferability of identified approaches and principles to other sectors, for example acute.
- Promote high quality nutrition and hydration practices, including the use of finger food where appropriate, and encouraging manufacturers to produce senior friendly accessible food where opening packaged food is required.
- Identify existing dementia specific wings or units in residential aged care facilities and hospitals, and appropriate respite and residential options especially in rural areas, for people with BPSD.
- Continue approaches to the Commonwealth Government regarding low admission rates of people with dementia who are recommended for residential aged care.
- Seek opportunities to provide support to residential aged 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.

71. 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.

Meeting diverse needs

- Identify specific barriers for people of diverse needs in accessing care and support.
- Support the development of appropriate service models to meet diverse needs.
- Support the development of strategies informed by the Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004–2009 (Australian Health Ministers Advisory Council).
- Support GPs to access appropriate medical care for diverse needs, for example to liaise with psychogeriatricians.
- Encourage collaboration between aged care facilities and community programs which are appropriate to diverse needs groups.
- Encourage the use of appropriately skilled and experienced bilingual bicultural people and bilingual personal carers to assist in the process of accessing appropriate care, and using appropriate respite.
- Identify and promulgate good practice literature and existing service models to meet diverse needs. For example, CALD friendly/specific and cluster models within residential care facilities which incorporate overnight respite with a centre-based day respite service.
- Promote the use of interpreter services in SRS and residential care facilities.

What does your organisation do?

The Bundoora Extended Care Centre (BECC) Aged Care Assessment Service (ACAS) Behavioural Support Team has been established to ensure that people living in their own homes and in residential facilities who have dementia and are exhibiting 'challenging' behaviours, are seen as soon as possible by the ACAS. The aim is to avoid inappropriate hospital admissions or premature change in level of care. The service is short term, and coordinates the level of assistance required to safely support a person in their familiar environment.

Services provided include:

- rapid ACAS assessment
- GP liaison
- geriatrician access
- additional short term allied health services as required
- organisation, coordination and purchase of extra support services as required, for example, nursing and personal care
- behavioural management plans, individualised to assist unpaid carers
- unpaid carer support and education, both consultation and direct 'hands on' care.

6 Evaluation

Evaluation of program specific funding remains as directed through individual Department of Human Services program areas.

Evaluation of the achievements arising from the dementia framework will be undertaken on an iterative basis, and in dialogue with the sector as implementation continues over the next five to ten years. An evaluation framework will consider the range of achievements resulting from both new and existing initiatives, as they relate to the stages in the pathway of dementia.

Table 2: Evaluation considerations

Pathway stage	Evaluation considerations
A. Healthy and active living, which may assist in preventing or reducing the risks of dementia	<ul style="list-style-type: none"> • Examples of promoting positive ageing, and social connectedness • Increased evidence of early life planning • Examples of awareness raising activities on life long lifestyle messages to meet diverse needs, using established community networks and media
B. Early stages on the dementia pathway	<ul style="list-style-type: none"> • Examples of promoting positive ageing, and social connectedness • Increased evidence of early life planning • Evidence of increased education and information • Examples of service development and enhancement • Examples of innovative models of support for people with dementia and their carers • Examples of action/progress in the area of respite and residential accommodation • Examples of information, services and training meeting diverse needs
C. Middle stages on the dementia pathway	<ul style="list-style-type: none"> • Feedback from Public Advocate regarding forward planning • Information regarding service development and enhancement including access and care management • Examples of innovative models of support for people with dementia and their carers • Examples of action/progress in the area of respite and residential accommodation • Examples of information, services and staffing meeting diverse needs
D. Late stages on the dementia pathway	<ul style="list-style-type: none"> • Examples of innovative and flexible models that delay or ease transitions from living at home to residential care • Examples of service development and enhancement • Examples of innovative models of support for people with dementia and their carers including access to counselling and social support • Examples of action/progress in the area of respite and residential accommodation • Examples of appropriate responses, practices and models meeting diverse needs

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	Service Development, Aged Care Branch DHS
Coopted Member	
Carol Pyke	Continuing Care and Clinical Service Development, 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 Department of Health & Ageing (DOHA)
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 and Clinical Service Development, DHS
Catherine Thompson	Manager Service Development, Aged Care Branch DHS
Diane Calleja	Service Development, Aged Care Branch DHS

Appendix 2

List of submissions to *Dementia Framework for Victoria, 2005 and Beyond Consultation Paper*

The many contributors are acknowledged for their time and contributions. While a submission may have been received from one organisation or agency, it is recognised that many individuals may have contributed to the drafting of the response.

- Aged Care Assessment Service, Victoria
- Aged Services Network, Western
- Alzheimer's Australia Vic
- Austin Health
- Australian Physiotherapy Association Victoria Branch
- Bairnsdale Regional Health
- Ballarat Health Services
- Baptist Community Care
- Barwon Health
- Benalla and District Memorial Hospital
- Bendigo Health Care Group
- Brotherhood of St Laurence
- Care Connect
- Carer Respite Centre Gippsland
- Carer Respite Centre/Carers Choice - Ballarat
- CarerLinks North
- Carers Victoria
- Caulfield General Medical Centre
- Cognitive Dementia and Memory Service (CDAMS) Statewide Coordinators Group
- Central Bayside Community Health Service
- Central Gippsland Health Service
- Centre for Development Disability Health Victoria
- City of Greater Dandenong
- Cobden District Health Services
- Consumer
- Council on the Ageing
- Dental Health Services Vic
- Department of Veterans Affairs
- DHS Central -
 - Continuing Care Branch, Metropolitan Health and Aged Care Services
 - Disability Services
 - Aged Care Branch program areas
- Health and Wellbeing, Disability Services
- Hospital Admission Risk Program (HARP) /Hospital Demand
- Mental Health
- Nurse Policy Branch
- Primary Health
- Office of Housing
- DHS Gippsland Region
 - Aged Care
 - Agency Liaison Officer
- DHS Hume Region
 - Community Aged Care
- DHS Loddon Mallee Region
 - Regional Director
- DHS Southern Metropolitan Region
 - Coordinated Care
 - Health Promotion Officer
 - Supported Residential Services (SRS) Program
- Diversitat
- DutchCare Ltd
- Eastern Health
- Fronthitha Care
- General Practice Divisions of Victoria Ltd (GPDV)
- Goulburn Valley Division of General Practice
- Goulburn Valley Health
- Headway Victoria
- Home Nursing and Support Service
- Inglewood and District Health
- Inner South Community Health Service
- Involuntary Carers
- Killara Eastern Health
- Kingston Aged Care Assessment Service (ACAS)
- Kingston Centre
- LaTrobe Valley Mental Health Service
- Melbourne Health
- Ministerial Advisory Council of Senior Victorians (MACSV)

Mount Eliza Centre
MPower
MS Society of Victoria
Network of Carers with a Mental
Illness
Northeast Health Wangaratta
Otway Health and Community
Prahan Mission
Queensland Health
Royal District Nursing Service
Shire of Yarra Ranges
Silver Circle
Southern Health
St Laurence Community Services
St. Vincent's Health/St Georges
Health
Sunshine Hospital
The Royal Australian and New
Zealand College of Psychiatrists
Uniting Aged Care Victoria and
Tasmania
Victoria University
Victorian Quality Council
Villa Maria Society
Wangaratta Rural City Council
Werribee Mercy Hospital
West Wimmera Health Service
Western District Health Service
Wimmera Health Care Group
Yanada House

Appendix 3

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, together with features which may vary from individual to individual.

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.
- Electroencephalogram (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, or inappropriate behaviours such as shop lifting.
- Early signs of disinhibition, such as unrestrained sexuality, violent behaviour, or 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 the person has 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.
- 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 practice 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:
 - ◆ Psychomotor slowing, bradyphrenia.
 - ◆ Loss of cognitive flexibility.
 - ◆ Reduced new learning.
 - ◆ 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 depression and dementia.

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 people 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.

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, or 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 (CDAMS) Peter James Centre,
Burwood East*

*Cheryl Donohue,
CDAMS Austin & Repatriation Medical Centre,
Heidelberg West*

Appendix 4

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.

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.
- 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.
- 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.
- 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 unpaid 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 unpaid 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 workers, there is increasing focus on involving unpaid carers who wish to be involved in care and support of their loved one, or in other ways in the facility. Behavioural and psychological symptoms of dementia – BPSD (described by health professionals as challenging behaviours) diminish as a person in the late stages of dementia becomes more dependent on others.

Based on:

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

Appendix 5

Services in Victoria for people with dementia and their unpaid carers

Stage on dementia pathway	Program title and organisation
Early	Cognitive Dementia and Memory Services (CDAMS), with referrals from service organisations, including: General Practitioner (GP), Aged Care Assessment Service (ACAS), Home and Community Care (HACC), and Community Health
	Carer Education and Workforce Training (CEWT), Managing Change, Drawing the Threads, Information Sessions, Providing Care in your Own Home - Alzheimer's Australia Vic (AAV)
	Dementia Support for Assessment Program - Aged Care Assessment Service (ACAS)
	Flexible Support for Carers of People with Dementia - Carer Respite Centres and other service organisations
	Home and Community Care (HACC)
	Low level and high level aged care facilities service organisations
	Planned Activity Groups (PAGs) - Home and Community Care (HACC)
	Services provided by Carers Victoria
	Supported Residential Services (SRSs)
	Support and Links, Memory Lane Café, HelpLine – Alzheimer's Australia Vic (AAV)
	Support for Carers Program (SCP) and other programs - Carer service organisations
Middle	Aged Persons Mental Health (APMH) Community Teams
	Carer Education and Workforce Training (CEWT), Managing Change, Drawing the Threads, Information Sessions, Providing Care in your Own Home - Alzheimer's Australia Vic (AAV)
	Carer Links
	Dementia Support for Assessment Program - Aged Care Assessment Service (ACAS)
	Flexible Support for Carers of People with Dementia - Carer Respite Centres and other service organisations
	Home and Community Care (HACC)
	Linkages – various organisations
	Low level and high level aged care facilities service organisations
	National Dementia Behaviour Advisory Service (NDBAS) - Alzheimer's Australia
	Planned Activity Groups (PAGs) - Home and Community Care (HACC)
	Services provided by Carers Victoria
	Supported Residential Services (SRSs)
	Support and Links, HelpLine - Alzheimer's Australia Vic (AAV)
	Support for Carers Program (SCP) and other programs - Carer service organisations

Stage on dementia pathway	Program title and organisation
Late	Aged Persons Mental Health (APMH) Community Teams
	Community Aged Care Packages (CACPs) – various organisations
	Carer Education and Workforce Training (CEWT), Managing Change, Drawing the Threads, Information Sessions, Providing Care in your Own Home - Alzheimer's Australia Vic (AAV)
	Carer Links
	Carers Victoria
	Low level and high level aged care facilities service organisations
	Palliative Care
	Support and Links, HelpLine - Alzheimer's Australia Vic (AAV)

Appendix 6

Draft *National Framework for Action on Dementia 2006–2010*

The draft *National Framework for Action on Dementia 2006–2010*, anticipated for release in 2006, contains strategies for State, Territory and Commonwealth Governments. Various strategies and actions to be undertaken by the Commonwealth support the identified needs of Victorians with dementia, and their families and unpaid carers. These strategies and actions are indicated below.

Commonwealth Government Responsibility

In the draft *National Framework for Action on Dementia 2006-2010*, the Commonwealth Government takes main responsibility for:

Care and Support Strategies

- Undertaking service planning and development to meet the needs of people with dementia and their families and unpaid carers. Milestones include mapping service pathways.
- Developing and or identifying effective and appropriate cognitive assessment tools to assess and screen people with dementia or who may develop dementia.
- Incorporating dementia care standards in residential care.
- Planning to meet the demand for residential care places for the future.

Information and Education Strategies

- Undertaking a dementia literacy survey as a baseline of public awareness.
- Establishing national linkages between specialist dementia information services and other information services.

Research

- Establishing and reviewing key areas for national research.
- Identifying current and new funding sources for dementia research on agreed research priorities.
- Promoting the results of research including in community, acute and residential care.
- Researching the projected prevalence of dementia, including prevalence among groups of diverse needs.
- Establishing uniform and effective data standards and systems which can be used in all jurisdictions and which ensure dementia data items are included in key minimum data set (MDS).

Workforce and Training

- Developing new resources to manage challenging behaviours.

Commonwealth, and State and Territory Governments Responsibility

In the draft national framework, the Commonwealth Government takes responsibility with the States and Territories for:

Care and Support Strategies

- Assessing service gaps for people with dementia and their families and carers, and incorporating dementia sensitive practices into service planning.
- Evaluating and validating diagnosis and assessment tools.
- Seeking to incorporate dementia standards into community care and acute care standards.
- Supporting primary health care professionals and encouraging GPs to broaden their skills in identifying, referring and caring for people with dementia.
- Identifying and promoting the best ways to assist people with dementia and their families and carers to navigate community care.
- Reviewing, developing and promoting flexible respite care models.
- Developing educational and training initiatives for health professionals and community care service organisations that inform them about palliative care and the needs of people with dementia.
- Developing service models and funding arrangements for the assessment, care, support and accommodation of people with dementia and behavioural issues.

Access and Equity Strategies

- Identifying the specific barriers of people with diverse needs to care and support.
- Developing appropriate service models to meet the needs of diverse groups.
- Developing ATSI specific strategies informed by the Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004-2009 (Australian Health Ministers Advisory Council).

Information and Education

- Referring issues of legislative barriers around guardianship, advance care planning, advance care directives, wills and powers of attorney to all government Attorneys General and Justice Departments.
- Developing and undertaking community awareness programs based on agreed key messages including targeted information campaigns to specific community groups.
- Increasing the awareness of broader service organisations that interact with people with dementia and their families and carers.
- Establishing links between specialist dementia information services and other information services.
- Establishing strategies to address elder abuse.

Research

- Disseminating to key stakeholders and the workforce key areas for research.
- Implementing data standards around dementia data items.
- Translating research into practice, through identifying and implementing ways to enhance practice.

Workforce and Training

- Identifying and promoting dementia related workforce issues.
- Reviewing incentives and barriers to participation in dementia care.
- Including dementia in training and curricula for relevant health, community care and aged care professionals.
- Promoting flexible strategies for professional development, such as Telehealth.
- Promoting interdisciplinary professional development
- Promoting existing and new resources and effective training strategies to care for people with challenging behaviors.

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