

# **THE DEMENTIA EPIDEMIC: ECONOMIC IMPACT AND POSITIVE SOLUTIONS FOR AUSTRALIA**

Prepared for  
**ALZHEIMER'S AUSTRALIA**

by



Canberra  
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The analogy of the receding tide on piii is drawn from Jorm (2001), paraphrased, in turn drawn from Gavin Andrews (St Vincent's Hospital, Sydney). Photo from [www.williamjosephgallery.com](http://www.williamjosephgallery.com). The fifth epidemiological transition is detailed in Broe (2002).

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***The receding tide***  
**The next epidemiological transition**

A century ago, Australia's birth rate was much higher, but few people survived to old age. With better sanitation, the dangers of the past – infectious diseases and childbirth – became far less serious threats to our health. As the tide of infectious diseases receded, the rocks that were always there were exposed – systemic degenerative diseases such as cardiovascular disease and cancer. But, gradually, even these problems are receding as we see the benefits of prevention programs and the better treatments possible with new technologies, particularly new surgeries and drugs. As the tide recedes further, the new rocks to be revealed are the neuro-degenerative diseases that strike the brain most often in old age. It is predicted that the neurodegenerative disorders will over the next two decades replace the systemic disorders as the major causes of both death and disability. Managing the challenges presented by these diseases, most notably dementia, will be the overwhelming priority of health care in the 21<sup>st</sup> century.

## EXECUTIVE SUMMARY

*Australia needs to move towards more positive public awareness of dementia, encouraging the community to view this disabling condition with more optimism and hope. We have a long way to go in understanding its causes and best treatment practices. Managing the dementia epidemic presents huge and growing challenges in terms of prevalence, costs and burden of disease. However, with appropriate research, funding and prioritised coordinated strategies for home-based, community and residential care, it is possible to minimise these burdens, enhance the quality of life of many Australians with dementia and their families and carers, and move forward this century with world class models of care and prevention, until a cure is found.*

The dementia epidemic has arrived. In Australia there were over **162,000 people** with dementia in 2002, including **6,600** under 65 – with ‘younger onset’ dementia.

- The prevalence of dementia is growing rapidly – reaching the 500,000 mark around 2040.
- Dementia is more common than skin cancer, yet with significantly less investment in public health initiatives.

In Australia, **dementia already costs \$6.6 billion** - \$5.6bn in real economic costs and \$1bn in transfer costs.

- **Direct health costs:** Dementia is the most expensive mental health item in Australia, costing \$3.2 billion in 2002, dominated by residential care costs (\$2.9 billion). By the end of the decade, these costs will nearly double. In addition, home and community care costs are also rising steeply; currently \$175m of Federal community services program money is spent on people with dementia.
- **Real indirect costs:** These are dominated by carer costs (\$1.7 billion) valued at replacement cost, together with the lost earnings and mortality burden of patients (\$364m) and the cost of aids and home modifications (\$120m).
- **Transfer costs:** \$592m of tax is foregone each year for people with dementia and their families and carers. Carer payments represent another \$324m, while additional welfare payments total \$52m.
  - *By mid-century, dementia costs may exceed 3% of GDP, from nearly 1% today.*

The socio-economic and disability burden of dementia is severe.

- 98.5% of people with dementia are disabled and use medical services more than the age-average.
- People with dementia have lower than average incomes and are under-represented in the workforce – 2.3% compared to the Australian average of 8.5% for people over age 65.
- Dementia cost over 117,000 years of healthy life (disability adjusted life years or DALYs) in 2002, and severe dementia has the highest disability weight of all conditions, equal with severe rheumatoid arthritis and higher than terminal stage cancer.
- Dementia is the second largest cause of disability burden in Australia after depression, and will become the largest by 2016, continuing to outpace other chronic illnesses.

***Dementia costs more years of healthspan than any of the national health priority areas.***

Strangely, the enormity and priority of the dementia epidemic have not yet been acknowledged in national policy making. Dementia has links to recognised national health priorities including cardiovascular disease, diabetes and depression, and it is the mostly costly area of mental health. *A national strategy to realise the vision, is long overdue.*

A national strategy must address current **constraints** to delivery of services for dementia, including:

- **General practitioners (GPs)** are generally poor at diagnosing dementia and could be assisted through greater access to specialists services (eg, memory clinics) and education and training programs, which could assist in diagnosis and ongoing support and management. Early diagnosis means the person and the family benefit from drug treatments, support and planning.
- **Acute care:** Average length of stay (ALOS) is prolonged and there is a lack of understanding about dementia in acute facilities, which could be addressed through broad-based training and awareness programs, as well as capital needs such as dementia-friendly and secure environments.
- Early access to **cholinesterase inhibitor (CEI) drugs** through the Pharmaceutical Benefits Scheme (PBS) is impeded by an overly rigid definition of acceptable benefit, the exclusion of people with non-Alzheimer dementia, and a cost-cutting approach that ignores the economy-wide benefits of pharmacotherapy as investment in wellness.
  - Comparative static cost-benefit analysis across the whole population of people with dementia shows that, by deferring institutionalisation for one year and delaying progression of illness, cholinesterase inhibitors can save up to \$49,219 per entry avoided (a 7:1 return on investment) plus a 13% increase in healthspan.
- **Research** is severely underfunded, yet there is scope for huge savings from investment in research for cause, prevention and care.
  - \$1 is spent on research for each \$342 of the total costs of dementia (0.29%).
- Despite welcome growth in **home and community services**, there remains unmet need resulting from barriers to access that would be eased by continued additional funding in each of the major programs. The lack of dementia-specific expertise needs to be addressed.
- In terms of **support for families and carers**, new innovative models should be implemented, in particular for respite care. Often the respite care that is available is inappropriate for people with dementia, and as a consequence there is a sub-optimal take-up rate (64%) of residential respite places. There need to be incentives to encourage increased employment participation for families and carers.
- There is a need for substantially expanded dementia and person-centred care **education and training** across the care sector, for families and carers and care workers. New models of care need to be trialled and utilised.
- Better use could be made of the services of cost-effective community organisations such as **Carer Associations** and, in particular, **Alzheimer's Associations**, which are limited due to funding constraints. Additional funding is required for programs such as the Dementia Education Support Program (DESP), the Early Stage Dementia Support and Respite Program (ESDSRP) and the Carer Education Workforce and Training (CEWT) project to deepen penetration rates and ease carer burden.
- Within **existing residential care**, there are multiple issues. Some of these include:
  - the descriptors in the Resident Classification Scale (RCS) currently do not accord well with assessments of Aged Care Assessment Teams (ACATs) or with appropriate placement of people with dementia, and need to include behaviour and environmental aspects;
  - sustainable pricing needs to be addressed within the context of the current federal Residential Aged Care Pricing Review, in particular capital costs for high care and recurrent costs for low care facilities;
  - current staff-to-resident ratios, staff training and nursing and care staff remuneration appear inadequate for quality dementia care;
  - firmer accreditation and monitoring of standards are required with tighter restrictions placed on chemical and physical restraint practices and more emphasis on person-centred care;



- planning ratios do not make provision for dementia-specific care;
- better access to appropriate care is required for people with dementia with serious psychiatric symptoms, as well as those with serious mental health problems who develop dementia;
- cluster housing campus models are needed that can cater well for a range of different needs as a person ages, with facilities appropriate to various 'groups' (eg, people with younger onset dementia for whom co-residence with older people is inappropriate) and various stages of dementia.
- Access for different groups of **people with special needs** must be addressed, including:
  - people with younger onset dementia;
  - people from culturally and linguistically diverse backgrounds;
  - indigenous people; and
  - people in rural and remote areas, including better use of new information technologies in delivering services.
- Long term **intergenerational planning** including better insurance or savings vehicles is needed to finance future growth in dementia prevalence, care and costs.

A **national vision** is needed which acknowledges the challenges of the dementia epidemic, and that responds with a broadly scoped and positive agenda for future action to meet those challenges. A key premise of the vision is a commitment to increasing healthspan for Australians with dementia through prevention, care and cure. This commitment must come from all stakeholders through a nationally coordinated **strategy**. Quality chronic care models must be utilised to maximise returns from health resources that are becoming increasingly scarce as the demographic transition proceeds. Dementia must be **prioritised**.

- At present, although significant sums are spent on dementia care through the aged care system, there remains inadequate recognition of and planning for the special needs of dementia care in mainstream community and residential care. Strategic coordination of dementia does not fit completely comfortably within either the aged care or mental health portfolios.
- Whatever decision is taken on the most effective point of coordination, it is clear that a whole of government approach is needed. This is because dementia care is so broad ranging, covering aspects of aged care, community care, residential care, medical services, psychiatric and specialist services, pharmaceuticals, workforce and housing.

Apart from prioritisation, **five pillars** of a future national strategy for dementia should involve:

- 1) a significant investment in research for cause, prevention and care;
- 2) early intervention through improvement in diagnosis, and the provision of cost-effective pharmacotherapies;
- 3) comprehensive provision of support, education and respite services – in place in the community as far as is optimal;
- 4) quality residential care, appropriately financed, that are centred on the person with dementia and their family/carer; and
- 5) provision for special needs, including people with younger onset dementia, people with behavioural and psychological symptoms of dementia (BPSD), people from culturally and linguistically diverse backgrounds, indigenous Australians and people in rural and remote areas.

Detailed strategies and recommendations are provided in Section 4.3.



If, starting today, we embark on such positive strategies, Australia can lead the way in effectively and smoothly managing the dementia epidemic.

Advances in medical science cannot be predicted but the probability is that the total costs of dementia care will rise significantly to the middle of this century to 3% of GDP given the demographic ageing of the population. However, the current returns from expenditures on medication and carer support can be expected to reduce the total costs to government substantially below what they might otherwise have been, through delays in admission to residential care. Every year residential care is delayed saves the Government \$30,632 per entry avoided. And the quality of life of people with dementia, their families and carers will be enhanced through these interventions. It is for these reasons we have to tackle the constraints to services and invest in research.

## 1. DEMENTIA – THE EXTENT OF THE EPIDEMIC

### 1.1 EPIDEMIOLOGY AND AETIOLOGY

Dementia is a progressive and disabling condition, primarily of older persons, that can bring turmoil and anguish to those involved. The progression of dementia over many years is often categorised as mild (early stage), moderate (middle stage) and severe or advanced (late stage), before the person dies. Different people may have different symptoms at various times, depending on the parts of the brain affected and the characteristics of each individual. That said, symptoms can be broadly classified (Burns, 2001) as:

1. **Cognitive impairment:** Symptoms include problems with memory (amnesia), speech or understanding of language (aphasia), a failure to carry out physical tasks despite having intact motor function (apraxia), and failure to recognise objects or people despite having knowledge of their characteristics (agnosia).
2. **Psychiatric and behavioural features:** There may also be any of a range of psychiatric symptoms – such as depression, delusions<sup>1</sup>, hallucinations (visual and auditory) – and behaviours such as wandering, incessant walking or agitation. A number of behavioural features derive from a person's response to the confused situation in which they find themselves, such as repetition, following, crying or “confabulating”<sup>2</sup>.
3. **Dysfunction in activities of daily living (ADL):** In the early stages of dementia these can take the form of difficulties with shopping, driving or handling money. In the later stages more basic tasks are affected such as dressing, eating and bathing.

#### 1.1.1 Diagnosis

There are as yet no known biological markers for dementia, so clinical diagnosis is based on medical and psychiatric history; neurological and physical examination; tests (mainly blood tests) to rule out other conditions and record baseline levels of cholesterol etc; a ‘baseline’ evaluation of the person's ADL functionality, thinking and memory (such as the widely used Mini-Mental State Examination – MMSE<sup>3</sup> – or Abbreviated Mental Test Score); and a caregiver interview or questionnaire.<sup>4</sup> Magnetic resonance imaging (MRI), computed tomography (CT) and positron emission tomography (PET) reveal any brain atrophy (shrinkage) or evidence of stroke, and distinguish other brain disorders (eg, tumour, bleed) that may be more treatable. Scanning technology involving radiology, electroencephalography, blood and cerebrospinal fluid may in the future be able to identify characteristic plaques, tangles and other markers of dementia, formerly identifiable only in autopsy (Alzheimer's Association US, 2002a)<sup>5</sup>. Genetic testing presents serious ethical implications for families and clinicians (Black et al, 2001 p4, 21). Black et al (2001) provide a good current summary of diagnostic processes and issues in Australia.

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<sup>1</sup> Examples are that a carer is ‘trying to poison me’, “trying to put me away” or “stealing my money”.

<sup>2</sup> Confabulating may involve providing an answer that may not be true, but could be, since the real answer is unknown – eg, “What did they give you for dinner?” Answer: ‘Fish, I hate fish!’ Reality: Lamb and vegetables.

<sup>3</sup> MMSE tests orientation (time of year and current location), ability to absorb and retain information (delayed recall of the names of three objects), level of attention, ability to calculate (count backwards from 100 by 7s) and competence in responding to instructions (“Take a piece of paper in your right hand, fold it in half and put it on the floor.” MMSE scores are usually around 18+ for mild illness (maximum is 30), 10-18 for moderate illness and less than 10 for severe illness. It can be poor at detecting very mild dementia and has biases in relation to education and culture.

<sup>4</sup> For example, IQCODE (Informant Questionnaire of Cognitive Deficits in the elderly).

<sup>5</sup> A team at the Brigham and Women's Hospital, Boston US, achieved high accuracy in diagnosis of AD with single photon emission computed tomography – SPECT (*Neurology*, June 1998). The National Institute of Aging in 2002 reports a powerful new imaging technique, multiphoton microscopy. Advances with functional MRI are reported in Black et al (2001, p19-20).

Differential diagnosis and assessment by a specialist is important, in particular distinguishing dementia from “normal” memory and cognitive impairment of ageing, and from other disorders such as delirium, major depression, drug abuse, amnesic disorder, anaemia<sup>6</sup> and others. It is also important to distinguish between the different types of dementia, which can have different features of onset, treatment and progression, often measured by the Clinical Dementia Rating Scale or Alzheimer's Disease Assessment Scale - Cognitive Subscale (ADAS-Cog). Diagnoses by trained doctors are 80%-90% accurate. Internationally recognised diagnostic criteria for dementia are:

- *DSM-IV*: Impairment in memory and at least one of the following: agnosia, apraxia, aphasia or executive functioning impairment.<sup>7</sup> Cognitive deficits are severe enough to interfere with occupational/social activities and represent a decline from previous level.
- *ICD-10*: Decline in both memory and thinking, of a degree sufficient to impair function in daily living.

### **To tell? And how to tell...**

*“I don't know if June knew she had Alzheimer's. She may have had an idea because her brother and sister had it. We never sat down and talked about it. Later when I did refer to dementia, it was a bit hard to know how much she was taking in. I think she felt it was all part of being old. She once said to me that she had retired, like I had.”*

‘Jack’<sup>8</sup>

A survey of 281 GPs in the UK found that only 39% would inform their patients of a diagnosis of dementia, compared to 95% who would inform them of a diagnosis of terminal cancer (Black et al, 2001). Reasons for not telling include emotional distress and other negative impacts for the person and their family, fear of incorrect diagnosis, a judgement that there is no benefit in the person knowing, or a request from the family or carer not to tell.

However, there is no evidence that this information has long-term negative effects – rather, the diagnosis may help explain confusing symptoms. Moreover, people have a right to know about their own health, and information is likely to bring the best health outcomes in terms of ability to become informed and supported, to know what to expect, to make plans and strategies for managing the illness and associated disability, to facilitate access to services including medical treatments and community services, and to enhance the relationships between the person, their families and carers and health professionals. Indeed, the earlier that these processes begin, the better.

In telling a person about a possible diagnosis of dementia, many skills are required. There may be suspicions and questions early on and, before compelling evidence is accumulated, the possibility of dementia is canvassed. Primary care professionals need to be truthful about what is happening, about the possibility of and reasons for both a correct or incorrect diagnosis, and provide sufficient verbal and written information and referral so that the person and their family can understand and adjust to the implications and options available. It may be beneficial for the person and a significant family member to be informed together. Sufficient time should be allowed to respond to emotional reactions, which are likely to include shock and grief that need to be expressed in healthy ways. Compassion needs to be exercised, a team approach adopted, and written information, support, counselling and referral offered.

<sup>6</sup> Other common physical tests include liver and kidney function, vitamin levels in the blood, thyroid function and blood glucose levels (diabetes). The physical examination may include checking pulse and blood pressure, and for any signs of stroke, chest or heart abnormalities or abdominal lumps.

<sup>7</sup> *Executive functioning* – the ability to think abstractly, plan, initiate, sequence, monitor and stop complex behaviours.

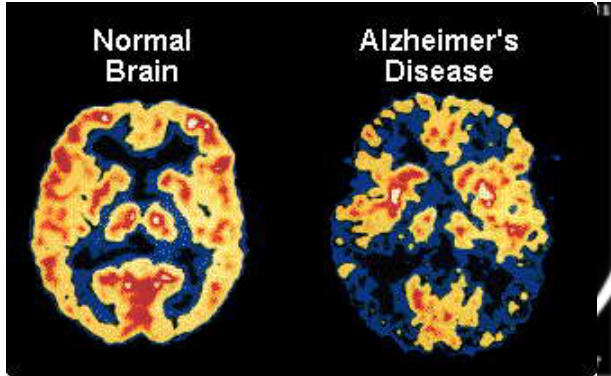
<sup>8</sup> A number of quotes in this document are extracted from personal stories collated in Hampson (2000). Where these are cited in this document they are sourced to the original storyteller.

### 1.1.2 Types of dementia

There are numerous diseases that cause dementia. A fuller list is provided in Wimo et al (1998, Table 1.1.2, p6). The most common types are outlined below, noting that they can occur together.<sup>9</sup>

**Alzheimer's disease (AD)**, the most common of the dementia disorders (comprising 50-70% of cases), is progressive, degenerative and currently incurable. The shrinkage or atrophy of the brain due to nerve cell loss can be seen during life on a brain scan, as pictured below.

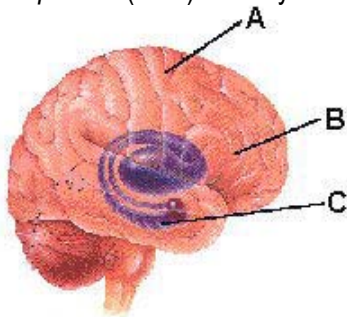
#### PET scans: Dementia involving AD<sup>10</sup>



A person with dementia may appear healthy on the outside, but on the inside, irreversible brain damage is occurring.

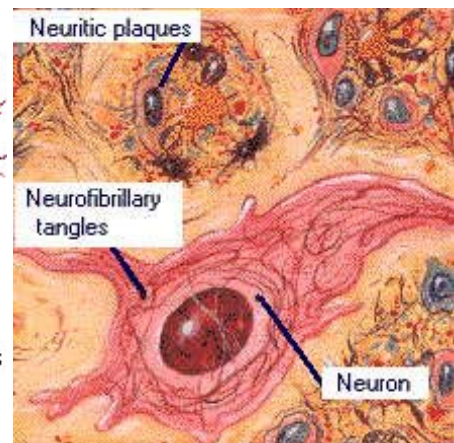
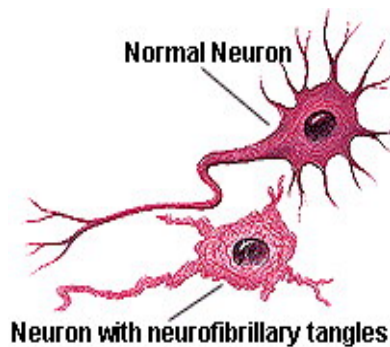
However, it is post-mortem analysis that confirms a diagnosis of AD, due to two key observations:

- neurofibrillary **tangles** within the nerve cell body. One theory assigns a causative role to the protein *tau*, which helps organise and stabilise a cell's internal 'skeleton', but which is deformed in AD, eventually aggregating into the tangles. This is a growing area of research.
- abnormal (senile) **plaque** deposits between nerve cells, containing the protein *beta amyloid* (A $\beta$ ). This is a prime area of research, to understand the abnormal processing of *amyloid precursor protein* (APP) which yields the A $\beta$  fragments.



#### Areas affected by AD

- A Cerebral Cortex
- B Basal Forebrain
- C Hippocampus



Alois Alzheimer, a German psychiatrist and pathologist, first published his findings on these 'tangles and plaques' in 1907. They occur consistently in people with AD and, interestingly, have also been observed

<sup>9</sup> The following sections utilise information from Burns A, Purandare N, Mann D and Bagley H, of the Personal Social Services Research Unit, *North West Dementia Centre*, University of Manchester, NHS Executive North West, UK, 2001.

<sup>10</sup> Images here and below courtesy of the National Institute on Aging, National Institute of Health, US, [www.nia.nih.gov](http://www.nia.nih.gov).  
Illustrator: Lydia Kibiuk.

in older people free from dementia. The ‘tangles and plaques’ disrupt normal electrical conduction of messages within the brain. A nerve cell chemical *acetylcholine* is also deficient in AD. Symptoms of AD can include:

- gradual memory loss
- decline in ability to perform routine tasks
- disorientation to time and space
- impaired judgement, abstract thinking and physical coordination
- difficulty in learning and concentration
- loss of language and communication skills
- changes in personality, behaviour and mood (up to two thirds of people with AD have depressive symptoms and about 20% exhibit aggression, more common in men)
- hallucinations (experienced by 16%) and delusions (false beliefs), often paranoid (30%)
- loss of initiative
- altered sleep patterns, eating disturbances and screaming.

Cummings (2001) lists the prevalence of neuropsychiatric symptoms that commonly accompany AD as agitation (60% to 70% of people), apathy (60% to 70%), depression (50%), anxiety (50%), irritability (50%), delusional disorders and psychosis (40% to 50%), disinhibition (30%) and hallucinations (10%). The symptoms and behaviours of AD, as well as the decreased functionality in ADL, can be physically and emotionally difficult for families and carers to manage, requiring person-centred care skills, ongoing training, understanding and support.

*“It is one of the truly heart-warming things about Alzheimer’s that so many partners and offspring quietly take on another’s chores and devote themselves, quite selflessly, to the care of someone they love.”*  
Hampson (2000), p54

*Disease progression:* Onset of AD is insidious and the disease lasts for 3-20 years (an average of 8) from diagnosis although average length of time from diagnosis may be increasing as people are now presenting earlier in the illness (previously diagnosis was made on average 2–3 years after onset of symptoms<sup>11</sup>). The first phase is typically around three to four years, characterised by mild symptoms of memory loss and disorientation requiring some assistance and surveillance (30% of diagnosed AD sufferers have mild disease). As the disease progresses, more difficulties with daily functioning occur and assistance with daily living is increasingly required. Moderate disease occurs in a further 40% of diagnosed AD cases. In the final years the disease is severe (the remaining 30% of diagnosed cases), with communication and movement problems and incontinence requiring high levels of specialised care, often in a nursing home setting.<sup>12</sup> Death is often attributable to pneumonia or infection.

**Vascular dementia (VaD)**, accounts for a further 20-30% of cases of dementia. These people appear to develop dementia from a narrowing of the arteries supplying the brain. The lack of blood can lead to many small areas of damage to the brain, each too small to be noticeable as a ‘stroke’ but collectively devastating in their effect. VaD is itself divided into sub-types:

- arteriosclerotic – reduced oxygen supply to the brain (chronic ischaemia);
- acute onset – following strokes;

<sup>11</sup> Brodaty H and Lie D, “Symptomatology: Functional Capacity and Behaviour” in Wimo et al (1998), p34.

<sup>12</sup> When institutionalisation is required depends on marital status, caregiver availability/burden and disease severity. Galasko et al (1995) found that about half the people developed severe symptoms within three years of onset, and two thirds within seven years.



- multi-infarct dementia – gradual onset following a number of mini-strokes (transient ischaemic attacks) in the outer brain (cortical areas);
- subcortical or Binswanger’s disease – demyelination (loss of the covering sheath of nerve fibres) affecting multiple sites in the deep white matter of the brain; and
- mixed cortical and subcortical VaD.

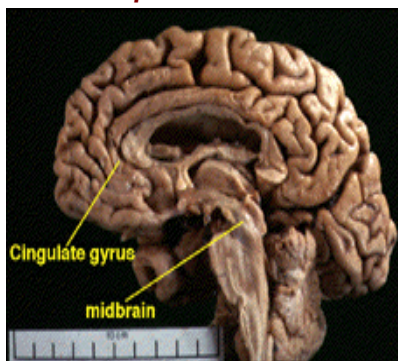
Like AD, VaD also results in symptoms that include impairment of memory, new learning, recognition, fine motor movements and planning and, since it is quite common for both VaD and AD to occur together (mixed dementia) it may be difficult to separate the two. VaD can be distinguished if there is:

- abrupt onset eg, following a stroke
- stepwise decline – severe worsening, then stability, then further deterioration
- patchy cognitive deficits eg, in memory but not so much in language
- less personality change and more insight into memory loss than in AD, where it is lost early
- more severe mood swings and more common depressive symptoms, hallucinations and delusions
- focal neurological signs and symptoms (eg, weakness or loss of sensation in part of the body)
- fluctuation in functioning – ‘good’ days and ‘bad’ days
- nocturnal confusion
- presence of vascular risk factors such as hypertension, diabetes.

*Disease progression:* As with AD, average survival is around eight years, although the course of VaD can be highly variable. In the early stages there may be only minor cognitive problems such as problem solving, planning and memory. There may be long periods of stability with abrupt stepwise worsening. Disease progression is more amenable to control by addressing the severity of underlying vascular risk factors. Cause of death is ultimately usually stroke or heart attack, or an associated chest infection.

**Dementia with Lewy bodies (DLB):** Lewy bodies are abnormal brain cells found in all parts of an affected person's brain, the hallmark of this type of dementia. DLB can be quite common (10% of all dementia), and has sub-types such as Diffuse Lewy Body Disease, Cortical Lewy Body Disease, Lewy Body Dementia, Senile Dementia Of Lewy Type, and Lewy Body Variant of Alzheimer's Disease. DLB is similar to AD with ongoing loss of memory, language and reasoning, and often the presence of AD-type senile plaques although seldom with significant neurofibrillary tangles. DLB, however, progresses much more rapidly than AD, and frontal lobe and visuo-spatial impairments usually occur earlier. Other features that differentiate DLB from AD include: motor traits of Parkinsonism, visual hallucinations, systematised delusions, REM disturbance, marked daily fluctuations, and falls and syncopal episodes (sudden loss of blood pressure resulting in fainting). In some families, DLB can be inherited.

***Brain of a person with DLB***



The diagram on the left shows the loss of nerve cells in the midbrain region where the *substantia nigra* is located (where dopamine is made), which also occurs with Parkinson’s disease. In both diseases, the dark-brown pigment called *neuromelanin* is also lost so the substantia nigra appears abnormally pale. Shrinkage of the brain is particularly seen in the temporal lobe, parietal lobe and cingulate gyrus. Lewy bodies can be detected by immunochemical staining for the protein *ubiquitin*. The protein *alpha synuclein* is a major component of Lewy bodies.

**Fronto-temporal [lobe] dementia (FTD):** also discovered by Alzheimer, in 1923, and commonly named after his colleague Arnold Pick ('Pick's disease'). It occurs in 1 in 5,000 people, but with earlier onset (even as young as 30-40), so is the second most common dementia of under-65's. Illness duration is longer – 10-15 years, with family history an important risk factor. Psychological testing and brain scanning (showing loss of tissue in the front parts of the brain) enable differential diagnosis. Symptoms are largely personality and behavioural changes, including restlessness and loss of inhibitions resulting in unsocial attitudes and actions eg, sexual disinhibition. Behaviours become repetitive and ritualistic, such as hoarding and food fads, with apathy and reduced or inappropriate speech as the disease progresses. Final stages include muteness. Post-mortem can show tangled bundles of proteins in nerve cells, similar to those of AD, as well as rounded ones called 'Pick bodies'.

**Parkinson's disease,** a progressive disorder of the nervous system, results from loss of the neurotransmitter *dopamine* in the brain. Dopamine is a chemical involved in communication between the nerves that control voluntary movements such as walking, talking and writing. It can take many years for Parkinson's disease to result in dementia, and indeed it may not always do so.

**Huntington's disease:** Huntington's disease is a hereditary disorder of the central nervous system affecting about 1 in 10,000 people. It often strikes in mid-life (ages 30-50) but ranges from 2 to 80, and runs a relentless degenerative course over a period of 10-25 years. Unusual jerking or twisting movements of the body ('chorea', its distinguishing characteristic) accompany the onset of dementia with cognitive and emotional elements. Other symptoms later on are muscle rigidity, and impairments to speech and swallowing (choking on food becomes a concern). Mortality is often from complications such as heart failure or aspiration pneumonia. There is now a presymptomatic blood test available although taking it is the prerogative of at-risk individuals. Cell death in Huntington's disease may be caused by a ball of protein that forms in the cell nucleus, with current research exploring possible drug treatments to prevent the accumulation of protein in cells.

**Creutzfeldt-Jakob disease,** is one of a group of disorders called human spongiform encephalopathies that, until recently, were extremely rare, with an incidence of about 1 in 2 million, onset normally between age 50 and 70 and with rapid deterioration. People may quickly pass from dementia symptoms into akinetic mutism (catatonic state) and die within 6 to 18 months. Recently a variant of Creutzfeldt-Jakob disease has arisen with younger onset (mostly people under 30), transferred to humans from animals with Bovine Spongiform Encephalopathy ('Mad Cow Disease'). In most instances the disease appears without any apparent obvious cause, although there are very rare inherited forms, such as Gerstmann-Straussler Syndrome (characterised by ataxia – loss of balance – and dementia with death after 3-5 years) and Fatal Familial Insomnia, as well as a transmissible form (once common in a Papua New Guinea tribe known as Kuru) and a few other medically induced cases. In most instances a definite diagnosis can only be made through post mortem, characterised by:

- swelling and loss of nerve cells, producing a widespread spongy change throughout the brain
- an increase in the size and number of brain cells, called astrocytes
- abnormal prion protein deposits between nerve cells, sometimes in large plaque accumulations.

Because of the long and variable latent period during which the disorder can be 'incubating' it is presently uncertain as to the extent to which iatrogenic Creutzfeldt-Jakob disease, especially the new variant form, might increase in future years. About 100 cases of the new variant have been confirmed in UK, where the risk is possibly highest.



### Younger onset dementia

Harvey (1998) reports epidemiological data and bottom-up costings for pre-senile dementia conducted by the *Dementia Research Group* in the UK. Specific findings, supported in other research, were that:

- AD and DLB were less common in younger onset dementia, while FTD was more common;
- prompt and accurate diagnosis is critically important in younger people because there is more likelihood that they are working, have children at home, have heavier financial commitments, have an inheritable form of dementia, and have difficulty obtaining a diagnosis and receiving care;
- the earlier treatment is commenced, the greater the possibility of recovery;
- neuro-imaging was under-utilised, which should be addressed through better primary care training;
- high levels of non-cognitive (psychological and behavioural) symptoms were identified in this population;
- individual packages of care services were required, which were often unavailable or underutilised by younger people (eg, community psychiatric services), with informal (family) carers filling the gap;
- levels of caregiver distress and burden were higher – over half of family carers were considered to have formal psychiatric illness, including depression, indicating that assessment and ongoing treatment of the family carer should be linked to that of the person with dementia;
- lower use of community services led to a lower estimate of financial costs for this component but shifted the burden to higher utilisation of institutional care – one third of the participants (under 65) were in institutional care compared to 15% aged between 65-74 (the requirement for residential care increases with age after age 65);
- residential care was estimated to have twenty times the direct costs of community care;
- costs increased slightly with increasing severity of disease, in part masked by the jump in costs of institutionalisation (people in residential care were in all disease severity groups);
- the study did not consider indirect costs, although concluding that these were also likely to be higher for younger people, due to the greater economic impact of work sacrificed for both the person and their younger carer;
- dementia in younger people was thus found to have higher *direct* costs than in older people – £7,189 to £7,868 (A\$20,636 to A\$22,586) per patient per annum;
- average cost of AD was second-lowest while VaD, FTD and alcohol-related dementia were highest (the latter most costly);
- enhanced coordination, communication and training of community resources commenced in response to the study, in order to better address the behavioural issues, reduce carer burden and distress and hence delay institutionalisation and provide more cost-effective care overall;
- more epidemiological ('bottom-up') studies of younger onset dementia need to be done, as there are so few with which to compare.

### 1.1.3 Aetiology

The causes of dementia are not well understood, although certain risk factors may be significant.

Dementia is *not* a 'normal' part of ageing

**Age:** Age is the most well-accepted risk factor, with the likelihood of dementia increasing from around 1 in a 1000 for people under 65, to 1% for people in their early sixties to well over 50% for people in their nineties.

**Family history:** Genetic factors contribute to dementia risk, particularly for certain types of younger onset AD. A clear inherited pattern of AD exists in less than 10% of cases. Several genes have been identified on chromosomes 21 and 14 in the familial type of AD. In the more common sporadic type, people with the e4 form of a gene for a protein called *apolipoprotein E* on chromosome 19 (*APOE-ε4*)

tend to have a higher incidence of AD than the general population.<sup>13</sup> In some cases of FTD, there is mutation of a gene on chromosome 17 that makes tau, inhibiting the protein's function and causing it to bundle up into tangles and Pick bodies. However, about half of cases do not have these changes in tau protein, although there are strong familial indicators for this type of dementia. In Creutzfeldt-Jakob disease, the prion gene is located on chromosome 20, with inherited forms the result of mutations in this gene, causing a 50% chance of children inheriting the disease from an affected parent. For Huntington's disease, there is a 'genetic stutter' - a stretch of DNA repeated over and over at one end of a gene on Chromosome 4. Much more work needs to be done to fully understand how genetics influences the incidence of AD. In addition, there is growing concern that genetic testing (eg, for the e4 allele) may lead to misunderstanding and that insurance companies or employers may misuse positive test results.

**Gender:** Over the age of 80, women are at slightly higher risk of AD, while men may be at higher risk of VaD. The Boston University School of Medicine Multi-Institutional Research in Alzheimer's Genetic Epidemiology study showed that by age 93, female risk is 13% higher than male risk. There is some evidence that higher risk in women may be due to post-menopausal hormonal changes.

**Cardiovascular risk factors, stroke-related and atherogenic causes** contribute to VaD and there is increasing evidence that they also contribute to AD – including high blood pressure (severe systolic hypertension), narrowing of the arteries (atherosclerosis), irregular heartbeat (atrial fibrillation), ischaemic heart disease and attacks (myocardial infarction), diabetes, high saturated fat and LDL cholesterol intake and smoking.<sup>14</sup> On-pump coronary artery bypass graft surgery may contribute to VaD.

**Education and employment:** One hypothesis is that higher levels of education or a lifetime of mental activity may increase the brain reserve by increasing the synaptic density in the neo-cortical association cortex (Stern et al, 1994). Other studies suggest that specific occupational exposures may increase AD risk, such as manual work (Fratiglioni et al, 1993) and exposure to organic solvents (Kukull et al, 1995) or electromagnetic fields (Sobel et al, 1995 and 1996), for example in occupations such as carpenter, electrician, machinist, sheet metal worker, typist or welder. If further research strengthens this evidence, and the link is not just socio-economic, there would be further rationale for preventive workplace measures such as shielding and separation.

**Other possible risk factors:** Psychiatric illness (especially depression) may also contribute to AD, as may previous thyroid diseases, head trauma, excessive alcohol intake, or aluminium (eg, in drinking water)<sup>15</sup>. Free radical damage to neurons (oxidative stress), probably the most significant cause of biological ageing, may contribute to dementia (Christen, 2000). Inflammation, involving cytokines and prostaglandins, may be another contributing factor to AD, primarily because beta-amyloid is an inflammatory protein (C-reactive protein is a marker of inflammation associated with AD)<sup>16</sup>. Glycation is a process central to aging, where *advanced glycation end products* (AGEs) are formed that may also be part of AD, as they have been found in the neurofibrillary tangles. There has also been the hypothesis that the immune system may gradually attack the brain as we age. Some brain disorders that cause

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<sup>13</sup> ApoE is a transport protein in lipid metabolism with three major isoforms – e2, e3 and e4 on chromosome 19. It is the e4 allele that is associated with increased risk of AD (e2 is thought to reduce risk). This is another area of research, as is the link with Down's Syndrome; nearly all people with Down's Syndrome (trisomy 21) who live into their 40s develop AD.

<sup>14</sup> A few studies have shown reduced incidence of AD among light smokers (fewer than 10 cigarettes per day), but increased incidence among heavy smokers (more than 20 cigarettes per day). Nicotine causes acetylcholine transmitter release and is thus theoretically of benefit in AD which has reduced acetylcholine levels.

<sup>15</sup> If AD is a possible long term outcome of head trauma, there is even more justification for public prevention activities such as compulsory seat-belts, helmets and restrictions on boxing. Aluminium, mercury, copper and other metals found in the brain tissue of people with AD may not cause AD, but result from the disease process. Further research is needed to clarify the roles of these metals in dementia. For more detail, see Alzheimer's Australia (2002b).

<sup>16</sup> A recent study on CRP as a marker (or playing a causal role) is in *Ann Neurol* 2002,52: 168-174.

symptoms similar to AD are caused by slow viruses. However, a virus specific for AD has not been identified. There has been some evidence of lower prevalence rates for AD in some developing countries and in rural areas, although the evidence regarding ethnic and cultural influences is unclear.

**Possible protective factors** that may reduce the risk of developing AD, include:

- **Use of pharmacotherapies:** The use of *anti-inflammatory drugs* (eg, in treating arthritis) – including both steroids and *non-steroidal anti-inflammatory drugs* (NSAIDs) – has shown a protective effect for dementia, triggering research on inflammation as a possible element of dementia pathology. Pooling data from many case-control studies show that people with prolonged use of anti-inflammatories have around *half* the risk of AD, and it is being trialled as a preventive therapy in high-risk individuals in the US. Taking *statins*, the most widely used cholesterol-lowering drugs, may reduce dementia risk by as much as 71%.<sup>17</sup> *Oestrogen* may well have a protective effect (up to 30% reduced risk), although there is contradictory evidence regarding postmenopausal hormone replacement therapy as the link may be educational and socio-economic. Further research is being undertaken in this area, such as the Women’s Health Initiative Memory Study, a large US trial.
- **Diet:** Recent studies have found that high intakes of antioxidants from food – vitamin C, vitamin E, and beta carotene, for example — may guard against AD.<sup>18</sup> Other studies have identified fish and seafood, wine and Ginkgo biloba consumption as having a potentially protective effect.<sup>19</sup> More recently, a Boston University study corroborated other evidence that the risk of contracting AD nearly doubles in people with high levels of the amino acid *homocysteine* (also a risk factor for heart disease), suggesting that consuming more folic acid and vitamins B6 and B12, which can reduce homocysteine levels, may also guard against AD (see also Section 1.2).

#### 1.1.4 Mortality

The dementia specific mortality rate is twice the rate of people without dementia – 2.4 (1.4-4.4) per 100 person-years, controlling for co-morbidities and socio-demographic factors. In Australia the crude mortality rate reported in 2000 was 19.1 per 100,000 (3,655 deaths), 26.3 for women and 11.8 for men, or 15.4 and 12.4 age-standardised respectively<sup>20</sup>. Age-standardised rates for people 85 and over are much higher at 982 for women and 641 for men per 100,000. 70% of people over 75 with dementia die within five years.<sup>21</sup> Death certificates grossly under-report dementia as the cause of death, often citing instead respiratory infection. AD is estimated to be the fourth leading cause of death in developed nations (after heart disease, cancer and stroke).<sup>22</sup> The number of deaths from dementia in Australia by age and gender is shown in Table 14 (Section 2.2.1), under-estimated for the reasons above.

*Dementia shortens life even in the very old. Iris Murdoch, prominent British novelist and lecturer, described her decline as “sailing into darkness”. Her husband and carer, John Bayley, comments on her death: “She is not sailing into the dark: the voyage is over, and under the dark escort of Alzheimer’s, she has arrived somewhere. So have I.”*

Bayley (1998)<sup>23</sup>

<sup>17</sup> “Statins Associated With Lower Dementia Risk”, *Harvard Medical School Family Health Guide: Chapter Update - Brain and Nervous System*, available on [www.health.harvard.edu](http://www.health.harvard.edu), October 2001 update.

<sup>18</sup> “Dietary Antioxidants May Decrease Risk of Alzheimer’s Disease”, *ibid*, August 2002 update.

<sup>19</sup> For example, *British Medical Journal* (fish), October 2002, the UK Alzheimer’s Society (ginkgo), October 2002, and *Journal of Neurology* (wine) November 2002 articles cited in Alzheimer Europe (2002).

<sup>20</sup> AIHW (2002a), p36-37, for this and the next sentence.

<sup>21</sup> Wimo et al (1998), p24.

<sup>22</sup> Life Extension Foundation (2002).

<sup>23</sup> Bayley’s book was made into a Miramax film, *Iris*, starring Judi Dench, Kate Winslet and Jim Broadbent. It sensitively depicts Bayley’s life with Murdoch “from their first meeting at Oxford through their struggles with Murdoch’s heartbreaking decline as Alzheimer’s disease eroded one of the keenest minds in contemporary literature” (<http://video.go.com/iris/>)

## 1.2 TREATMENT AND MANAGEMENT

Although there is no cure, there are ways to reduce risk factors, treat and manage the behavioural and psychological signs and symptoms of dementia (BPSD), and improve quality of life for the individual and family carer, through:

- promoting an understanding of what is quality dementia care;
- prevention and early diagnosis/intervention;
- psychosocial approaches including support, counselling, education and memory loss programs;
- use of medications (pharmaceutical and natural) to treat cognitive decline and memory loss;
- medical and surgical interventions;
- the availability of appropriate community services, including respite; and
- residential care services, including dementia specific services.

The progression of dementia, the variety of causes and differences in individual circumstances prevent any mechanical approach to treatment but the model of severity by types of care for patients with BPSD (see the “Brodaty Triangle” diagram after the Methodology section) illustrates the different levels of management that need to be in place.

### 1.2.1 Quality of care

Henderson and Jorm (1998) summarise quality care principles as:

- accurate assessment of the resident’s needs and functioning
- knowledge of the staff about dementia
- individualised care
- activities that are tailored to the individual
- appropriate attitudes of staff
- communication skills
- use of the physical environment<sup>24</sup>
- support for the family carer.

Rosewarne et al (2000) also emphasise the need for residential care facilities to own and practise a person-centred care philosophy, from senior management down, and apply it to day-to-day practices, care planning, behaviour management, staff appraisals, personal care routines, communication with relatives and activity programming. Features of quality care outlined below include the need to:

- redefine problems and understand behaviours* of people with dementia – ie, focus on the person and not just target the behaviours;
- plan and implement specialised *activity programs* – to stimulate interest and encourage activities designed to address specific psychosocial needs and preferences;
- personalise the care* – emphasising intimate knowledge of who the resident is – their history, family connections, values and current circumstances;
- give staff ownership and care responsibility* - build staff-resident relationships by subdividing large numbers of residents into small working groups, for whom designated care teams are responsible;
- create domestically scaled social environments* – cluster house designs, with kitchen-dining focus areas, have been successful in creating a homelike environment and building social interactions;

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<sup>24</sup> For example, ample space for safe walking.

- *provide flexibility of care routines and practices* – a relaxed organisational environment using strategies that focus on timing, routines and needs of residents, preventing resistive responses;<sup>25</sup>
- *cultivate professionalism of care and support of staff* – create a culture of doing something innovative, progressive and worthwhile, rather than a task-oriented ‘completion of jobs’ approach;
- *include relatives in the life and care of the resident* – expend effort to maintain continuity in the resident’s life through encouraging ongoing contact with family and others who can provide undivided personal attention.

### **Person-centred care philosophy**

Care is about the person behind the illness, and entering into their world. A fundamental premise is that all people are entitled to the best possible quality of life, with dignity, in comfortable surroundings and with the assurance that he or she has personal worth and is valued by others. ‘Challenging’ reactions and behaviours may be environmentally provoked and are rarer in a calm environment with trained staff who are understanding and take a personal interest in the residents and who promote a feeling of security. Sherman (1999) is an excellent book for carers, written from many years’ experience as an Australian carer in a residential setting and also caring for her husband, Bill, who had dementia. The book is rich with personalised examples of care that is full of skilled insights into the reasons for behaviours, patience, respect, wisdom and humane strategies for sensitively helping people.

For example, people with dementia may be prone to agitation, wandering, suspiciousness, inappropriate language or screaming, sexual disinhibition, apathy, self-injury, combativeness, repetitious demands or resistance to maintaining hygiene. In each case there is a need to seek the reason underlying the specific behaviour, and then as far as possible to meet the need - listening, responding, gently prompting, providing reassurance, company, respect, praise, etc. The following checks can also help:

- environmental modifications, such as limiting noise and glare from windows to reduce confusion caused by over-stimulation, putting calendars and clocks in many rooms, or playing soft music
- providing predictable but stimulating routines with structured times for daily activities and, if insomnia is a problem, cutting down caffeine, getting regular exercise and avoiding daytime naps
- explaining tasks beforehand, for example "Peter, I’m going to help you put on your shirt now"
- providing reassurance without challenging or contradicting accusations or misperceptions
- redirecting attention and use of light-heartedness and humour “The man in the mirror is taking his clothes off – you put yours on and he’ll put his back on too!”
- dignified precautions to help prevent wandering/intrusions”attacks” eg, disguised doors, signs
- recording behaviour patterns including frequency, timing and strategies that work with that person.

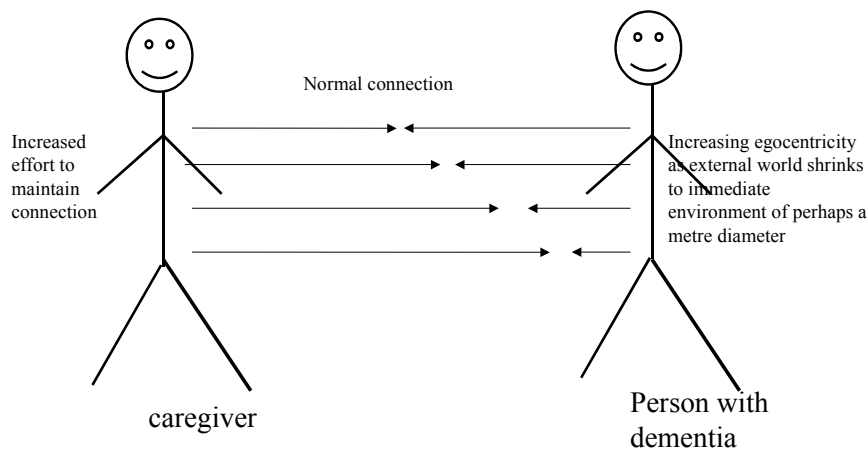
**Modelling:** *The three women who sit near the outside door are irritated by Bob, who no longer knows, and is beyond learning, how to manipulate handles and knobs. Several times a day he tries to go into the garden. Gripping the handle, he rattles the door. The women call to him to stop. ‘Go away, go away’ they tell him, as he becomes infuriated when the door fails to open. For the next day of two the nurse quietly opens the door for him. ‘There you are, Bob, you can go out now’, each time turning to the women to say, ‘He has forgotten how to open the door. He can’t help it, you know.’ From then on, one or other of the women opens the door for Bob, explaining to anyone who cares to listen, ‘He can’t help it, he’s forgotten.’ Staff praise them for their caring attitude.*

Sherman (1999)

<sup>25</sup> Rosewarne et al (2000, p66) describe this as “Flexibility and resident-centred care is a product of staff attitudes and organisational predisposition, a more even allocation of direct care hours throughout the day, multi-tasking approaches, resident-staff assignment models and a willingness to give more control to residents, or refrain from exerting control when not really necessary.”



### Establishing connection



A key to providing quality care is to provide effective connection (different from communication, which can be passive) between the person with dementia and the caregiver (either formal or informal). This is illustrated in the diagram at left. As dementia progresses, there is an increasing egocentricity of the person – their capacity

to connect to the world becomes increasingly smaller. Conversely, this means that any caregiver has to provide greater effort to establish and maintain connection. Connection involves caregiver time and skills, and thus is intimately related to costs of care in terms of dollars as well as emotional burden that, in turn, relates to financial costs in terms of carer support levels, staff turnover and training.<sup>26</sup>

Alzheimer’s Australia (2003) provides an excellent summary of the philosophy, care environment and key elements of quality dementia care. Current accreditation standards could be enhanced further to promote these aspects of quality dementia care. At present, the stated aims of standards and certification are to “provide a high quality of personal care to every resident, to have a safe building and to be committed to protecting their resident's rights”<sup>27</sup>. Standards cover all aspects of residents' needs from health and personal care and safety to a range of lifestyle matters including independence, privacy and dignity. Accreditation standards focus on:

- identification and compliance with all relevant State and Territory legislation, regulation, professional standards and guidelines (including those issued by Nurses Registration Boards); and
- maintenance of an adequate number of appropriately skilled staff to ensure that the care needs of residents are met, with an obligation of providers to ensure that the staffing skills mix reflects current resident care needs, and arrangements for the ongoing development of staff skills.<sup>28</sup>

Accreditation is granted through the Aged Care Standards and Accreditation Agency, with some 3000 residential aged care services currently accredited nationwide. Under the Aged Care Act 1997, the Commonwealth pays residential care subsidies – 75% of the cost of care for residents – only if accreditation standards are met, with sanctions imposed for non-compliance<sup>29</sup>. Monitoring involves scheduled visits and spot checks. The complementary certification process focuses on improving the physical environment in residential facilities, which led to over \$800m in capital investment between 1997 and 2001 when first phase accreditation was completed. Under the 1997 Act, a service must be certified to be able to charge accommodation bonds or accommodation charges or receive concessional resident supplements. All new buildings must meet privacy and space requirements while existing buildings must meet these no later than 31 December 2008.

<sup>26</sup> Diagram and concept courtesy of Virginia Moore, Dementia Services Consultant, Brightwater Care Group, with acknowledgement also of Perrin and May (2000).

<sup>27</sup> DHA, *Residential Care Standards and Accreditation*, available on [www.health.gov.au/acc/rescare/standard.htm](http://www.health.gov.au/acc/rescare/standard.htm)

<sup>28</sup> DHA, *Residential Care Manual - Chapter 11 - Accreditation and Quality of Care*, Sep 2002, available on [www.health.gov.au:80/acc/manuals/rcm/contents/11accr3.htm](http://www.health.gov.au:80/acc/manuals/rcm/contents/11accr3.htm)

<sup>29</sup> At the time of writing, 5 facilities Australia-wide had sanctions imposed, 2 in QLD, and 1 in each of NSW, SA and TAS.

### 1.2.2 Prevention and early diagnosis

**Prevention and research:** Prevention of dementia can involve either elimination (not yet possible) or, as for other chronic diseases of ageing, postponement of onset till later in the lifespan. The best chance for disease elimination is possibly related to stimulating an immune system response that destroys A $\beta$  (see Section 1.2.2).

**Postponing onset:** Addressing contributing medical or psychological factors (eg, cardiovascular factors, reducing head trauma) is important as either preventive or treatment measures – for example, cessation of smoking, balanced diet, regular exercise, modest intake of alcohol, controlling blood pressure and cholesterol<sup>30</sup> (eg, through *statins*, cholesterol-lowering drugs and reduced salt intake). Reducing stress may also be important. The preventive value of NSAIDs, oestrogen, antioxidants, anti-platelet treatment and reducing homocysteine through increased folate are discussed in the following sections.

**Research:** A number of dementia research activities are funded through the National Health and Medical Research Council as well as other public and private interests, although these are limited (see Section 3.2.5). There is scope to substantially increase research in prevention, treatment and cure:

- understanding of the biomedical causes of dementia;
- measures that can prevent or postpone the onset of dementia;
- new pharmacological therapies to slow and reverse disease progression (these may be just around the corner);
- epidemiological (population-based) medical and public health research<sup>31</sup>;
- effective models of care for people with dementia.

*“Alzheimer’s research is advancing at an accelerating pace. Recent discoveries support the notion that we may soon be able to delay the onset of the disease and allow people with Alzheimer’s disease to continue functioning independently for longer periods.”*

US Alzheimer’s Association

**Prospects for indicated prevention:** Indicated prevention is one step before early intervention, where people have minimal symptoms foreshadowing disease. Researchers have proposed the existence of a state of Mild Cognitive Impairment (MCI) – memory impairment beyond that expected for their age and education – which may be an indicator of high risk (10-15%) for developing dementia (Black et al, 2001). Jorm (2002) states that:

“It is only a matter of time before some drug is developed which actually slows progression. If such a drug were very cheap and had no side effects, we might want to give it to everybody above a certain age as a [selective] preventive measure. However, if it were expensive and had side-effects, as is more likely to be the case, it could be reserved for people with minimal symptoms, for example with MCI.”

<sup>30</sup> The Syst-Eur trial showed that people aged 60+ with systolic hypertension and randomly receiving anti-hypertensive drugs had 50% reduced incidence of dementia (AD and VaD) after two years. Another large trial underway is the PROGRESS trial, with results expected soon. Statins may reduce stroke risk by 29% and there is also evidence they lower the risk of dementia (Jorm, 2002).

<sup>31</sup> This research, together with awareness campaigns, has enabled diseases such as lung, skin and breast cancer to be seen as conditions with preventable elements subject to a public health approach.



Trials of such preventive interventions are already occurring, including for example one trial in the US comparing the effects of vitamin E and donepezil (Aricept) in preventing the development of AD in people diagnosed with MCI.

**Early diagnosis and intervention** helps those involved have more control over the disease and their lives. By early use of pharmacotherapies and by learning strategies to help cope with the many changes brought on by dementia, people are more able to live meaningful, productive lives for longer periods. Being able to recognise symptoms and obtain an accurate diagnosis early means:

- ❑ Drug and medical treatments can be commenced which benefit people most in the early to moderate stages;
- ❑ Reversible conditions (such as depression and delirium) can be treated, improving the prognosis;
- ❑ Financial and legal plans can be made, with the full agreement of the person with dementia;
- ❑ The individual and family can adjust better to the diagnosis, understand the illness and learn how to cope better through adequate counselling and education.

Early diagnosis means the person and the family can benefit from drug treatments, support and planning.

Pipher (1999) observes that taking a pragmatic, uncomplaining approach, as many older people (particularly males or people of English origin) may do, may not be helpful – their “stoicism is now called denial”. Hampson (2000) observes that “denial is a major issue in the delay of diagnosis of dementia, and even after diagnosis”. Many family members cannot come to terms with dementia or feel that it is stigmatised. Initially it can be harder to accept because of the lack of tangible “proof”. For others, the problem may be convincing the family doctor that something is wrong, when dementia symptoms are diagnosed as stress, tiredness, depression or ‘old age’. Even though this may be ‘comforting’, several years later the symptoms become too severe to ignore and precious time has been lost.

However, many GPs remain uninformed about advances in dementia assessment and diagnosis, have difficulty diagnosing dementia and do not refer the person with dementia on to community support services, although steps are being taken to address these problems (see Section 1.2.4 on GPs and 3.2.1 on cost-effectiveness of early intervention).

*“I still consider myself fortunate. I believe my early diagnosis led me to accept the disease more easily because I still retain powers of reasoning. It has allowed Mavis and me to become educated about the disease and to complete all the legal documents while I am still in possession of my faculties. Together we can make important decisions about my future treatment. My wishes can be discussed in a rational way without either of us becoming upset. For these reasons I urge the medical profession to make an early diagnosis and allow Alzheimer’s sufferers the time to make their own decisions.”*

‘Phillip’

Another important benefit of early intervention is the positive impact for the caregiver. A recent US study demonstrated that the well-being of the caregiver and care recipient are closely related, and in particular that the risk of clinical depression for the caregiver was higher if either the care recipient was depressed or agitated, or they themselves were in poor health. Early interventions for the person with dementia were thus found to also increase the level of health of the caregiver. Black et al (2001, p11) also point to evidence that early diagnosis can improve the health and coping skills of the family carer and delay institutionalisation.

### 1.2.3 Pharmacological management

**Anticholinesterase<sup>32</sup> (anti-dementia) drugs:** The chemical that breaks down acetylcholine is blocked by drugs called (*acetyl*) *cholinesterase inhibitors* or *CEIs*. They work best in the mild to moderate stages of AD – by the later stages so few cells are left that make acetylcholine, that even if their breakdown is protected there are still not a lot carrying messages. Evidence is also growing that they may be effective in VaD and dementia with Lewy bodies, and that use in later stages may also be beneficial. The situation is very much a moving feast. Numerous trials indicate that consistent prolonged use of the various anti-dementia drugs *delays* the progression of symptoms of dementia in the majority of people for nine to twelve months on average and possibly longer (see Section 3.3.1). There may be some improvement in clarity of thought, ADL functionality, mood and behaviour. The current drugs do not result in halting the progression of dementia, although studies are looking at the effectiveness of combination treatments to this end.<sup>33</sup> Side effects (which vary with each drug) may include nausea, vomiting, cramps, fatigue and loss of appetite, and are minimised if the dose is gradually increased, often settling down with time. There are four cholinesterase inhibitors currently available in Australia.<sup>34</sup>

- **Tacrine** (“Cognex”) was approved for marketing in Australia by the TGA in 1995, but two successive applications for a PBS listing were refused. Its use is thus uncommon in Australia.
- **Donepezil** (“Aricept” by Pfizer) was approved for marketing in 1998, but an initial application for PBS listing was turned down, ostensibly for cost-benefit reasons. The efficacy and tolerability of Aricept has been established, with Cochrane review concluding: “In selected patients with mild or moderate Alzheimer’s disease treated for periods of 12, 24 or 52 weeks, donepezil produced modest improvements in cognitive function and study clinicians rated global clinical state more positively in treated patients” (Birks, Melzer and Beppu, 2003). Results showed improvement from baseline ADAS-Cog and Clinician’s Interview-Based Impression of Change measures. Since then, Aricept has undergone extensive trialling against placebos and other drugs and in other contexts showing, for example, that people with moderate to severe AD may also benefit from treatment.<sup>35</sup>
- **Rivastigmine** (“Exelon” by Novartis) was approved for marketing in 2000 and both it and donepezil became available on the PBS from February 2001, after subsequent applications. Cochrane review concluded that: “Rivastigmine appears to be beneficial for people with mild to moderate Alzheimer’s disease. In comparisons with placebo, improvements were seen in cognitive function, activities of daily living, and severity of dementia with daily doses of 6 to 12 mg” (Birks, Grimley Evans, Iakovidou and Tsolaki, 2003). Longitudinal studies of ambulatory patients with mild to moderate AD suggest the gain on placebo may be an average 4.9 units (from 23 at baseline) after 26 weeks on the ADAS-Cog from 6-12mg Exelon daily.<sup>36</sup>
- **Galantamine** (“Reminyl” by Janssen-Cilag) was approved for marketing and PBS subsidy from 1 November 2001. Cochrane study concluded: “This review shows consistent positive effects for galantamine for trials of 3 months, 5 months and 6 months duration.... There is therefore evidence for efficacy of galantamine on global ratings, cognitive tests, assessments of ADLs and behaviour. This magnitude for the cognitive effect is similar to that associated with other cholinesterase

<sup>32</sup> Also known as cholinergic drugs, cholinesterase inhibitors, anti cholinestrators.

<sup>33</sup> For example, donepezil has been shown to improve aspects of cognitive functioning and on ADL in persons with AD (Saine et al, 2002). However, Phase III trials are showing that combination therapy of memantine and donepezil elicit a *sustained* improvement in cognitive function. See “Forest Labs’ Drug Combo Effective in Alzheimer’s Study” Monday 9 December 2002, Dow Jones report (New York).

<sup>34</sup> Medscape’s “New Treatments for Alzheimer’s Disease: Pharmacokinetics of ChEIs” *Drug Benefit Trends*, provides a concise comparative summary of the mechanisms of these drugs, usage, and side-effects. See also Alzheimer’s Association (2001b), including dosages, for this section and the prescribing information following.

<sup>35</sup> See Birks, Melzer and Beppu (2003 Cochrane Library) and [www.aricept.com](http://www.aricept.com), for product information.

<sup>36</sup> See [www.exelon.com](http://www.exelon.com) for product information.

inhibitors including donepezil, rivastigmine, and tacrine” (Olin and Schneider, 2003). Recent trials suggest galantamine may slow decline in cognitive function (memory, learning and problem-solving) by 12 to 18 months in mild to moderate patients who take 24-32mg daily consistently over three years ie, 50% delay in disease progression.<sup>37</sup> Reminyl is subsidised on the PBS to a maximum of 16mg/day.

The full cost of CEI drugs to government in Australia in 2002 is approximately \$160 per month. Rules for obtaining subsidised Aricept, Exelon and Reminyl through the PBS are complex. People must have a diagnosis of probable mild to moderate AD confirmed by a specialist (MMSE score of at least 10), with a baseline cognitive measurement (ADAS-Cog) if the MMSE is 25 or more. A diagnosis of VaD or dementia with Lewy bodies precludes the subsidy. Continuing to receive the subsidy depends on the results of reassessment within or after the first six months, which must show cognitive improvement of at least 2 MMSE points (or of at least 4 ADAS-Cog points if this was required). The subsidy then continues to be available until the doctor identifies that AD has moved into the severe stage, with reassessment every six months. The initial authority application (including test results), and the first ongoing authority (also including test results) must be in writing; there is no access to telephone, fax or email approval.<sup>38</sup> There are special provisions for people who have language difficulties affecting the test results eg, indigenous people, people from non-English speaking backgrounds and people with intellectual disabilities or illiteracy. PBS data shows around 18,500 Australians were using Aricept, Exelon and Reminyl in December 2002, some 16% of those with mild and moderate dementia or 23% of those with mild and moderate AD. There thus appears scope for increasing application to the target group.

**Aspirin and blood-thinning (anti-platelet) agents:** These reduce the risk that blood will clot and produce a stroke, as well as having anti-inflammatory properties (see footnote 43). Cochrane review stated that: “Aspirin is widely prescribed for patients with a diagnosis of vascular dementia; in one study, completed by geriatricians and psychiatrists in the UK, 80% of patients with cognitive impairment (with vascular risk factors) were prescribed aspirin” (Williams, Rands, Orrel and Spector, 2003). Although they form the mainstay of treatment to slow the progression of VaD, there is a division of opinion on their effectiveness. One side-effect of aspirin is increased risk of bleeding, particularly for high-risk people (eg, with duodenal or stomach ulcers).

**Other medications:** A variety of drugs are used to manage symptoms of depression (eg, insomnia), restlessness, hallucinations, hostility and agitation, and can help the involuntary movements and emotional disorders for some people with Huntington's disease.

Other existing new or upcoming drug therapies for dementia include:

- *future amyloid-based treatments:* research into amyloid processing has identified some potential therapeutical applications:
  - stimulating an immune system response that destroys A $\beta$ . Although the first immunotherapy to reach trials – the Alzheimer “vaccine” – was disappointing (Chapman, 2000), new ones under development show promise in preventing and possibly reversing AD<sup>39</sup>

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<sup>37</sup> See “Study shows benefits of reminyl may be sustained for at least three years for patients with alzheimer’s disease” on [www.janssen-cilag.com/news/detail.jhtml?itemname=c\\_02\\_news\\_jul02](http://www.janssen-cilag.com/news/detail.jhtml?itemname=c_02_news_jul02) See [www.reminyl.com](http://www.reminyl.com) for product information.

<sup>38</sup> International Psychogeriatric Association, 2001 and [www.health.gov.au/pbs/index.htm](http://www.health.gov.au/pbs/index.htm)

<sup>39</sup> Clinical trials of AN-1792, the investigational “Alzheimer vaccine” being developed by Elan Corporation and Wyeth Pharmaceuticals, were stopped in January 2002 after 15 participants developed symptoms of brain inflammation. However, new findings in late 2002, reported in *Nature Medicine* and *Nature Neuroscience*, by two groups of researchers provide evidence that the concept underlying the vaccine is promising and that modifications may be possible to make it safer. The

- *secretases* – are inhibiting enzymes that break up APP, thus reducing levels of A $\beta$  by affecting its cleavage and metabolism. These are a promising area of research currently at the clinical trial stage.<sup>40</sup>
- *p53 inhibitors* – the protein p53 helps damaged cells to die, thus defective p53 allows cancer cells to grow. In very recent research, new compounds are being developed to inhibit p53 in the brain, keeping cells alive longer and protecting the brain from A $\beta$ .<sup>41</sup>
- *memantine*, available in the EU and undergoing Phase III trials in the US, is a non-competitive N-methyl-D-aspartate antagonist that blocks the action of *glutamate* (glutamate can over-stimulate the nervous system and become toxic to nerve cells). Memantine has had positive response in the Clinical Global Impression of Change and the Behavioural Rating Scale for Geriatric Patients (BGP), particularly the 'care dependence' sub-score. It is very promising, particularly in combination therapy.<sup>42</sup>
- *hormone replacement therapy* – oestrogen and progesterone supplementation continue to be investigated, though opinion is mixed (Fillit, 2002) – see possible protective factors (Section 1.1.3).
- *anti-inflammatories* – including preventive effects of long term use of NSAIDs (Zandi et al, 2002)<sup>43</sup>, ibuprofen, Cox-2 inhibitors. Anti-inflammatory drugs may warrant future trials, although they can have potentially dangerous side effects so preventive benefits may only outweigh risks in very high-risk individuals.
- *possible new acetylcholinesterase inhibitors* – research is continuing in the hope of improved anti-dementia drugs which may further slow the progression of dementia – one such (metrifonate), seemed promising but was withdrawn after a number of adverse effects. More recently, *phenserine*, a third generation acetylcholinesterase inhibitor with dual action, reducing APP and A $\beta$  formation, has possible potential to further slow progression of AD and other dementia.<sup>44</sup>
- *MAO-B inhibitors (anti-oxidants)* – notably selegilene (Eldepryl or Deprenyl), a drug approved for use in Parkinson's disease, which may have a long-term helpful effect on memory in mild to moderate AD through a number of pathways – reducing free radical damage, anti-apoptotic (reducing programmed cell death as per p53 below) protecting cells from the toxic effects of A $\beta$  and increasing nitric oxide production which increases cerebral blood flow (Life Extension Foundation, 2002).
- *nerve growth factor (NGF) supplementation* – stimulates neuronal cell growth, survival and repair, and is a promising area of research, with trials now underway.<sup>45</sup>

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study showed 60% reduction in plaque formation in mice, using an antibody that blocks the CD40-CD40L protein. Because there was also a reversal in established plaque formation, this research holds hope as both a prevention and a cure.

<sup>40</sup> Secretases are the same category of enzymes targeted by the protease inhibitors that have revolutionised AIDS therapy. Researchers led by Dr Michael Irizarry at Massachusetts General Hospital concluded their mid-2002 tests showed "clear support for beta-secretase activity as an important target for therapeutic intervention" *Arch Neurol* 2002; 59:1367-1368.

<sup>41</sup> *Journal of Medicinal Chemistry*, 7 November 2002, cited in Alzheimer Europe (2002).

<sup>42</sup> "Ebixa" (by Merz) is a trade name for memantine released in October 2002 in the UK.

<sup>43</sup> This study was of 3,227 over-65s in Cache County, Utah, and found that long term use (more than two years) resulted in 45% the incidence of dementia in non-users, with even greater protection for longer term users, and provided the use occurs well before the onset of dementia. Aspirin compounds showed the best results, but these were strong also for ibuprofen, naproxen, diclofenac, nabumetone, sulindac and oxaprozin, as well as histamine H<sub>2</sub> receptor antagonists (H<sub>2</sub>RA). Non-inflammatory pain relievers used as controls had no effect on dementia risk.

<sup>44</sup> See for example, National Institute of Ageing [www.nia.hih.gov](http://www.nia.hih.gov) and "Phenserine shows potential to slow or stop progression of Alzheimer's disease", April 4 2002 on [www.seniorjournal.com](http://www.seniorjournal.com)

<sup>45</sup> There are now trials of NGF proteins on humans, also for stroke, spinal cord injury and other nerve-damaging conditions (Gustilo et al, 1999). Experiments on rats have shown that NGF promoted growth of new synaptic connections in a part of the brain called the hippocampus, which could help restore memory loss and potentially reverse AD.

- *nimodipine*, a calcium channel blocker, can be of some benefit in the treatment of patients with dementia, cerebrovascular disease, or mixed AD and cerebrovascular disease; however, its short-term benefits probably do not justify its use as a long-term anti-dementia drug (López-Arrieta, 2002).
- *piracetam*, a derivative of gamma-aminobutyric acid, also used in Europe for the treatment of memory loss and other cognitive defects. Piracetam has beneficial effects on the fluidity of membranes from the hippocampus of people with AD (Muller, Eckert et al, 1999). In a Hungarian study, MMSE scores increased, with particular improvement for memory, concentration- psychomotor speed and depressive symptoms (Tariska and Paksy, 2000).
- *aminoguanidine* could be of value in reducing AGEs in AD, but requires large clinical trials if merit is to be established (Ramamurthy et al, 1999).
- *nefiracetam* may be useful in AD due to its ability to stimulate nicotinic acetylcholine receptors (Nishizaki, Matsuoka et al, 2000).
- *metanicotine*, which is less toxic than nicotine and causes nearly the same acetylcholine release, is currently under clinical studies for use in AD.

#### **1.2.4 Natural / alternative treatments**

Many natural, traditional or alternative treatments are used with dementia<sup>46</sup>, including:

- *acetylcholine support* – eg, lecithin (phosphatidylcholine)
- *antioxidants* – Ginkgo biloba (see below), Vitamin C, Vitamin E, Acetyl-L-carnitine, N-Acetyl cysteine; some studies show Vitamin C may be protective but evidence for Vitamin E is more mixed.
- *anti-inflammatories* – essential fatty acids including omega-3 and omega-6, docosa-hexaenoic acid, eicosa-pentaenoic acid, gamma linolenic acid and S-adenosyl methionine (S-AMe).
- *homocysteine reduction* – Vitamin B12, Vitamin B6, folic acid, S-AMe (particularly if depressive signs); trials are now underway exploring the effects of increased folate on VaD.<sup>47</sup>
- *nervous system support* – methylcobalamin (the neurologically active form of vitamin B12), phosphatidylserine, inositol, Vitamin K, idebenone, *melatonin* (particularly if there is insomnia) and tryptophan.
- *Early morning sunlight exposure* – for people who suffer sleep disorders and night wanderings as a result of damage to the pineal gland (which produces melatonin), together with a strict routine of sleep, meals and social activities.
- *AGEs inhibitors* – Vitamins B1 and B6, carnosine.
- *herbal treatments* – huperzine A, kut, curcumin (turmeric).

Of these, Ginkgo biloba, derived from the leaves of a Chinese tree, has recently come under new scrutiny for its anti-inflammatory, anti-oxidant and anti-platelet properties. A 2002 British review of 33 clinical trials since 1976 concluded: “Overall there is promising evidence of improvement in cognition and function associated with Ginkgo. Our view is there is need for a large trial using modern methodology to provide robust estimates of the size and mechanism of the treatment effects.”

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<sup>46</sup> More detail on alternative treatments, as well as pharmacotherapies, is provided in Life Extension Foundation (2002).

<sup>47</sup> Homocysteine is a by-product of a wide variety of chemical reactions in the body, possibly associated with AD as well as VaD.



*"I decided not to use Aricept because it is far too expensive. I wanted to see how good the herbal things are, and so far they are doing a wonderful job. I take ginkgo biloba and vitamin E, 1000mg/day. They have been crucial, and I have noticed the effect. I also take fish oil, aloe vera, lecithin, B complex and vitamin C. These have all helped me immensely. There is a fellow at my early onset group who has dementia and had been virtually housebound for three years, very disoriented and confused, lost all his confidence. I noticed he had started to slur his words. I told his wife to get him into the ginkgo and vitamin E. That was about six weeks ago. I saw him at a meeting recently and the improvement was incredible... To talk to him you wouldn't know he had dementia, and he had actually been down to Sydney for a little holiday – on his own!*

*'Cathy'*

### **1.2.5 Other medical and surgical interventions**

**General practice:** The GP plays a key, long term role recognising, assessing, planning, managing, referring, coordinating and supporting the person with dementia, and their family carer. The GP's role is very important from the early stages of the diagnostic process (especially differential diagnoses), through relationship and life planning, learning strategies, prescribing medications, co-ordinating referral to specialists and to community care, arranging admission to hospital and attendance at nursing homes. As the illness progresses, the family or carer will seek the GP's advice more on behalf of the individual – so there are in effect two patients, not just one.

However, surveys showed that, in 1998, only about half of GPs were able to recognise mild dementia and about 70% were able to identify moderate dementia (Creasey and Brodaty, 1998). Many GPs find it difficult to differentiate between depression in older people and dementia. One key difference is that people suffering from depression are more aware of the problem and more likely to complain about symptoms (Blackmun, 1998).

In 1998, Australian psychogeriatrician Professor Henry Brodaty developed a questionnaire to help GPs make early diagnoses of dementia (see Section 3.2.1). Feedback from GPs has been very positive, and it is hoped that the questionnaire will assist a higher rate of early diagnosis in the future. Moreover, with better treatments and tests now available, GPs may now be more interested and able to diagnose AD.

GPs may also not be as effective as desired in acquiring up-to-date information on dementia and dementia care, understanding the family's and carer's role and accessing a range of local support services available at different times. "Shared-care" initiatives, aimed at spreading information between GPs and other aged care professionals, are under way to help inform and resource GPs for ongoing care.

Because most people with dementia are elderly, they may also suffer a number of other disorders, which need to be treated by the GP alongside dementia (unless the illness is very advanced and an express desire not to treat at such an occurrence was documented when the person had mental capacity). In many cases this requires the GP to be up-to-date on the most recent pharmacotherapies, their subsidisation arrangements and their interaction with other drugs for concurrent ailments of ageing.

***"Please remember this: If we want GPs to play a central and continuing role in the care and management of their patients who have dementia, they need to be trained in the role and remunerated accordingly."***

Alzheimer's Australia (2001a)

**Specialists:** Specialist neurologists, psycho-geriatricians, psychiatrists, physicians in geriatric medicine and other consultant physicians are important in undertaking initial assessments of people for diagnosis, as well as ongoing assessments and treatment of people with dementia, including prescription of medications, management in wards and nursing homes, and so on. There may be a battery of cognitive and behavioural tests, for example the Dysfunctional Behaviour Rating Instrument, to assess each major cognitive and behavioural domain as well as functionality in ADL. Tests for depression and delirium may also need to be conducted, for example the Geriatric Depression Scale. Caregiver input or direct observation are important in assessing functionality, as overstatement of abilities can be an issue. Occupational therapists can assist in functional assessments.

A neuropsychological assessment takes 45 minutes to two hours and possibly longer for people with mild dysfunction. Strategies need to be put in place to avoid anxiety, which can affect test performance. Computerised instruments are now an alternative to paper-based tests, requiring less assessor time and enabling a more accurate recording of time spent, although people need to be comfortable with the use of computers. Assessors need to consider factors that may influence test performance.

Other specialist therapies can include those listed in Section 1.2.4 under “specific therapies” and possibly surgical intervention (see below), while the disproportionate use of specialist services is shown in Section 1.4.4. Specialist involvement in memory clinics is noted in Section 1.2.8.

**Hospitalisation:** As with other older people, acute care services are occasionally required by people with dementia, whose average length of stay (ALOS) is four times that of people without dementia (DHA, 2000). Part of the reason for the long ALOS may be that individuals are awaiting entry to long-run facilities, triggered by the event which led to the stay in acute care – a fall, for example. Acute care hospitals are not always well equipped to cater for the special needs of dementia patients, however.

**Surgery:** Two controversial potential **surgeries** are in the experimental stage, a shunt for cerebrospinal fluid and a more radical omentum transplantation.

- **Shunts:** A shunt can help drain the A $\beta$  protein fragments away and increase the flow of cerebrospinal fluid (CSF). Dr Gerald Silverberg, a Stanford US neurosurgeon, published results<sup>48</sup> showing that experimental shunts in a small trial had slowed disease progression, with safe overall outcomes. An expanded, multi-centre, controlled clinical trial is now underway (Allen, 2002; Barclay, 2002; Ajmani, 2002).
- **Omentum transplantation** - Dr. Harry S. Goldsmith, at the University of Nevada School of Medicine, places part of the *omentum* – a biochemical-rich membrane of fat and blood vessels in the abdomen – directly on the brain. This is claimed to improve symptoms in people with AD, although further research is warranted to explain how (and how effectively) this surgery works.

### 1.2.6 *Psycho-social interventions*

**Counselling and psycho-education:** Appropriate counselling through all stages of dementia progression is very helpful for the individual and the family. Psycho-education can help the person and their family learn to manage certain symptoms - such as cognitive behaviour therapy to address misbeliefs (delusions) - and can help prevent secondary morbidity such as depression or anxiety.<sup>49</sup> Because of the strong emotional impact of a dementia diagnosis, particularly younger onset dementias

<sup>48</sup> *Neurology* (2002) 52:1126-1127, 1139-1145, 22 October.

<sup>49</sup> For example, in treating depression resulting from moving Ms W to the confining environment of nursing home following the independence of hostel accommodation, medication and hospitalisation were not helpful. Identifying the source of the problem, loneliness, and organising a volunteer companion a few hours a day, resolved the depression.



where there may be the additional stress of the knowing that children may be at risk, family counselling and/or participation in support groups can be very helpful. Personality changes can be very difficult for spouses and families; for example, flat affect and low motivation that can be perceived as loss of love.

### **The problem-solving approach**

Each problem is as unique as each person. There is no single tolerable solution and contributing factors may include the person's background, environment, habits, reactions and feelings. There are three steps in planning the problem-solving approach:

1. Defining the problem
2. Assessing the person in the situation
3. Planning a strategy to solve the problem.

Miss Perkins causes a commotion each evening when she refuses to shower. After consulting her sister, we restore her lifelong routine of showering in the morning and dressing 'ready for work'. The problem is solved.

As a sales manager, Mr Grant frequently ate in expensive restaurants. At the day centre, having no money to 'pay' for his meal and leave a tip for the 'waitress' distresses him. He eats little. His wife supplies him with some coins, restoring his dignity – and his appetite.

In her broken English, Mrs Berger repeatedly tells staff: "I worried ... going to ask me leave ... nowhere go." If a member of staff accompanies her to her room, points to her name on the door and opens cupboards so that she can see and touch her clothes, she is content for a few hours. On the other hand if she is ignored or told she is mistaken, she becomes agitated, noisy and demanding. She goes to her room, picks up the flexible shower hose in her bathroom and sprays around the room shouting, 'Not mine, not mine.'

Sherman (1999)

**Specific therapies:** Physical, occupational and speech-language therapies can assist with specific problems – for example, an occupational therapist can help maximise independence while identifying necessary modifications in the home or in driving. Diversional, reminiscence, validation, music, movement/dance and craft therapies may be useful to calm, comfort and occupy people with dementia, particularly when they involve loved ones. Swimming and hydrotherapy can also bring peace and quality of life. Massage, aromatherapy, light therapy, laughter, companionship and warm touch (from children or pets as well as other adults) may also be beneficial.<sup>50</sup>

Professor Faith Gibson, a leading proponent of reminiscence therapy in Northern Ireland, notes that people with dementia can have very good long term memories and that tapping into these provides a means of affirming and including people with dementia and enabling them to "shine, perform, get things right, rather than being constantly confronted with their shortcomings." Tools include old photographs, family albums and personal mementos, compiling 'this is your life' books with family and friends, questions about and listening to tales of the past, and so on.

Validation therapy affirms the utterances of a person with dementia through an interested or warm response, rather than ignoring or minimising them. For example, a word or behaviour may be constantly repeated, indicative of an unresolved worry. By validating the concern and asking sensitive questions about it, the therapist may be able to trace the source of the problem and allow relief, even closure.

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<sup>50</sup> For a recent study on the benefits of aromatherapy see Alistair et al (2002).

*“It is intuitively reasonable to expect that a life which involves the presence of others, which is stimulating through variety of experience during the day, and which calls for personal initiative or self-expression, will be preferable for persons with dementia.... There is no evidence as yet that a psychosocially enriched environment brings about any lasting benefit to cognitive function, but it does promote the quality of life of patients, and is of considerable importance in maintaining high standards of nursing care.”*

Henderson and Jorm (1998)

Music therapy has also been recommended to increase melatonin in the blood, as well as helping people to relax (Kumar et al, 1999). Musical ability and enjoyment may remain intact, as with long term memory, even into late stage dementia, and bring great joy and shared experience.

*As a child, I recall visiting my grandmother and great aunt who both suffered from dementia. By the time they were eventually placed in nursing care in Adelaide, neither could recognise me nor hold a conversation. My great aunt would count agitatedly for hours, while my grandmother went through a very aggressive stage, which may have been due in part to her frustration at losing language skills. However, both would become calm and contented if my mother and I began to sing with them. As though there was no problem, they would join in with gusto to songs in English and, in the latest stages, in their native tongue, continuing to sing peacefully even after my mother and I had left to go home.*

The author

**Multicultural issues:** Although people from non-English speaking backgrounds may have been fluent in English, studies show that the most recent language is lost first for people with dementia. Sometimes a mix of native and second languages is used for a time. Translation may be of little help, but it can bring joy to a person to hear their native language spoken or played on tapes. It is estimated that 25% of Australia’s population aged over 60 are post-war migrants, and 25% of them have a non-English speaking background. 12% of people in residential care are from culturally and linguistically diverse backgrounds, with a variety of cultural customs, traditions and values. The composition of this group will continue to vary, from Eastern European, now at their age peak, to those from Southern Europe, the Middle East and Asia, who will peak later. These Australians have equal right to access affordable, quality dementia assessment and care services, which can only be available for them if specialist resources are developed to promote access. There is some evidence that people from some non-English speaking backgrounds may present later to services such as memory clinics, even if there is a bilingual specialist available.

**Peak community bodies:** Community organisations such as Alzheimer’s Australia and Carer Associations are able to help meet a wide range of needs, including for information and resources about understanding and managing dementia (libraries, pamphlets and electronic links), counselling (phone and face-to-face), support groups and membership benefits, programs for people living with early stage dementia and for management of BPSD<sup>51</sup> and so on, referral services, family carer education, training and support (through courses and seminars in community, hospital and residential settings), advice on issues like driving, legal and financial planning for future health care needs, including preparing advance directives such as a living will, power of attorney, consent to participate in clinical trials, palliative care and so on. Peak community bodies are also of key importance in advocacy and promoting public awareness, as for example 57% of adults are unaware of the links between cardiovascular risk factors

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<sup>51</sup> For example, the Alzheimer's Association's *Safe Return* Program, an identification program for memory impaired adults.

and dementia.<sup>52</sup> Peak bodies also deliver services such as mobile respite and federal programs. Alzheimer's Australia manages the following national programs:

1. The **Carer Education and Workforce Training Project**: CEWT provides competency based training and educational resources to families and carers and respite care workers.
2. The **Dementia Education Support Program**: DESP provides a basic level of support, education, and short term counselling to people with dementia and their families and carers. Through the National Dementia Helpline (1800 639 331) this core program provides a key access point to information, referral and counselling for people with dementia, their families and carers as well as other service providers.
3. The **Early Stage Dementia Support and Respite Program**: ESDSRP (usually referred to as the 'Early Stage' program) provides people in the early stages of dementia and their families and carers with information, education, counselling and support.
4. The **National Dementia Behaviour Advisory Service**: NDBAS is a national telephone service designed to assist families and carers and respite care workers manage behaviours of concern.

*"The course brought together people suffering from the same problem and there was an openness among us. Carers and sufferers were counselled in separate groups. People were able to discuss their problems without embarrassment. Many realised for the first time that they were not freaks and that they were not alone. We saw our problems and frustrations mirrored in others. As our familiarity grew, there was more chatter, laughter and, on some occasions, tears. At the end of the six weeks our understanding of the disease had increased and so had my confidence in my own ability to deal with it."*

'Phillip'

*"I continued my membership with the Alzheimer's Association and became part of a small, local support group. We met each month under the guidance of a professional social worker. We became a very close, caring group. We used to discuss very frankly what each member was going through. There was always someone who had already experienced a particular phase and could enlighten the others. We managed to see the lighter side of Alzheimer's and would tell each other about any amusing events – like the time Marjorie put the left-over roast through the dishwasher instead of back in the fridge. Our group continued to meet for eight years, after which everyone in the group apart from me had either lost their relative or placed them in care."*

'James'

Churches also provide a range of community services and support. Boden (1998) and others also point to the peace found in personal faith. Hampson (2000) states that: "Faith can play a critical role for a person with dementia, and the opportunity to talk about God or faith may offer immeasurable comfort and be life-affirming."

*"Everyone is going to 'the other place' eventually; I want to do what I can to make my life as positive as possible. My friends have been terrific. The Christian community has been absolutely wonderful. Everybody says to me, 'You're so peaceful'. It's having God in my life that has made me that way. That's what gives me strength."*

'Cathy'

<sup>52</sup> For details of this North American and European survey, see "Two thirds associate dementia with the ageing process", [www.NewsRx.com](http://www.NewsRx.com) 23-9-02.

### 1.2.7 **Caring for families and carers**

*Carers Australia* estimates there are at least 2.3 million Australians (one in every five households) providing care for family members or friends with a disability, chronic condition or who are frail aged. Nearly 20% (450,900) of these are 'primary' carers for people at home with severe or profound disability. 70% are female and 90% are aged 60-69. Conservative estimates show that the 'invisible workforce' saves the economy \$16 billion annually and is the major provider of community care services, delivering 74% of all services to people needing care and support (compared to the HACC Program, worth \$1.1 billion in State and Federal funding, which meets only 9% of this need).

Most primary carers (78%) are of workforce age (aged 18 to 64 years) yet paid work is usually not possible - 59% are not attached to the workforce. Over one-half of all full time carers reported incomes of less than \$200 per week, while also experiencing the increased expenses of looking after another person. 40% of primary carers have been providing care for a decade or more, and 68% for more than 5 years. 43% care for a partner, and 21% for a parent, and most primary carers (54%) said that they provided care either because alternative care was unavailable or too costly, or because they consider they have no choice. Carers suffer from generally worse physical health, tiredness, stress, back/muscle problems, depression, anxiety and lack of respite.<sup>53</sup> For carers of people with dementia, specific additional stressors may also include:

- difficult behaviours and symptoms, most commonly incontinence and the need for constant supervision – days can be full of frustrations are repetitive chores;
- broken sleep;
- the emotional involvement of the carer, for example, mourning the loved one's former competencies and the loss of future hopes and plans;
- ambiguities about their role as a carer – how long to continue, how and where to seek help, (perceived) lack of support from other family members, "mistakes"/"failure" when there is no clear definition of "success", the impact of caring on the carer's life ("taking over");
- impacts on the carer's relationships, eg. strain on marriages for carers of parents; and
- social isolation – friends disappear, it can be difficult to leave the house and social events are rare.

*"The greatest cry I hear is that people feel they have no friends. Friends stop coming. I try to encourage people to keep going. Even if they just sit. Quite often there are things you can do to help."*

'Jack'

Stressors tend to be lower, the better the quality of the past relationship between the person with dementia and their family carer. Professional carers – service providers – can also, needless to say, experience considerable burnout and stress. Counselling, regular medical checks, education, information, support and respite services are essential for families and carers, result in improved health outcomes for families and carers and patients, and reduce or delay the demand on (more costly) community and residential services. Carer programs are outlined in the previous section. Costs and benefits of dementia carers programs are elaborated further in Section 3.3.



**Above: Bill helps his wife Diane with a card game.**

<sup>53</sup> Sources: AIHW, *Australia's Welfare: 1999 Services and Assistance*; Carers Australia, *Caring Costs*, 1998, Australian Bureau of Statistics, *Disability, Ageing and Carers: Summary of Findings*, 1998. Cited on Carers Australia website.

"It presents a challenge to a family to come to accept that this downhill course is pretty inevitable, and yet may be slow, and that the caregiver's needs almost certainly will increase as time goes on," said Dr Williams, a geriatrician who formerly headed the National Institute on Aging. "And yet, the person who's affected may still be functional in a number of ways and may still get some enjoyment out of things they enjoyed earlier," he noted. "It's a challenge to spot the things they still can get pleasure from... A former housekeeper can contentedly fold the same laundry day after day. President Reagan's biographer reported that he enjoyed scooping leaves out of his swimming pool. Once he completed the task, Secret Service agents accompanying him would surreptitiously add more and he'd keep going."

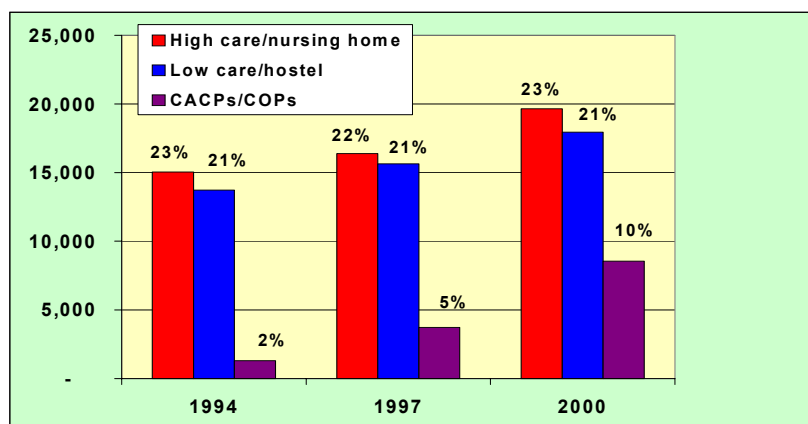
Rotstein (2000)

### 1.2.8 Care in the community

"Ageing-in-place" – bringing services and care to older people in their homes rather than moving them to the services – has become a guiding social principle in most Western countries, including Australia since the 1985 Aged Care Reform Strategy, due both to concern for cost efficiencies as well as the general premise that most older people prefer to remain in their own homes as long as they are able.

Aged Care Assessment Teams (ACATs) – multidisciplinary teams linked with regional aged care teams and located in public hospitals (inpatient and outpatient areas) and community health centres – assess and identify the physical, medical, psychological and social needs of older people and their families and carers, linking them to appropriate support services (eg, specialised rehabilitation services) and managing comorbidities. ACATs generally include a combination of a geriatrician, nurse, social worker, occupational therapist and physiotherapist. They assess around 185,000 people a year, making recommendations about whether the appropriate care setting for each individual should include additional community services and support, and which ones – a rising component in recent years as shown in Chart 1 - or whether they are eligible for Commonwealth-funded hostel (low-care) accommodation or entry to a (high care) nursing home, these being fairly constant at 43-44% of recommendations. Moving to special dwellings such as hostels of various forms (group housing for supported independent living) or residential nursing care may become desired as needs grow for greater security, access to services and living comfort. The search for options between the extremes (home-based, nursing homes) is producing a spectrum of diverse alternative arrangements along the care continuum.<sup>54</sup>

**Chart 1: ACAT assessment rates and recommendations for services, Australia**



Source: Access Economics derived from appendix data in AIHW (2002a), Table A31.1

<sup>54</sup> See Johansson, Chapter 1.4 in Wimo et al (1998).



A range of support services is available in the community, both privately and publicly, including home care, adult day care, day hospitals, and education and respite services for families and carers. The definition of community care is imprecise but includes personal care, health, accommodation and social services for people with dementia and their families and carers, provided outside of formal institutions. The Department of Health and Ageing definition is:

*“Community care describes a diverse range of services. Its main aim is to enable people to remain living in their own home and community. Community care is provided under a variety of programs that are funded by both Federal and State Governments. Community care is accessed by a variety of people including: older people, younger people with disabilities, carers, people with mental illness, people with acquired brain injury, people with chronic illness and people with dementia. Most community care programs charge their clients a fee for service. The fee is often quite minimal.”<sup>55</sup>*

**Memory clinics**, first developed to provide outpatient services for people with mild dementia, are a useful and important solution to coordinating dementia assessments and supporting the person with dementia, the family carer and the GP. Some of these are State-funded, including 14 Cognitive Dementia and Memory Services (CDAMS) in Victoria since 1997. CDAMs are multidisciplinary clinics including a specialist geriatrician, nurse, allied health professional and/or social worker and have access to psychologists, psychiatrists, counsellors and other allied health professionals. Memory clinics have marked acceptability amongst doctors, people with dementia and their carers, and are especially useful in improving assessment, with some randomised trial evidence for positive impacts on carer health.

Community support services, such as Meals on Wheels, can be particularly important for single people living alone with dementia. Publicly provided community assessments for singles can make recommendations and help with issues such as home modifications (eg, enclosing upper storey balconies), reminder alarms, lowering hot water temperature, removing electrical items from wet areas, introducing a daily dose box for medication, changing bulbs and labelling essential items. It may be more difficult with singles for families to identify the right time to move into residential care. Children who live elsewhere and phone or visit daily may not be on call to treat a fall or emergency immediately, precipitating an earlier entry into residential care than might be possible if co-located.

In Australia around half those diagnosed with dementia live in the community, assisted by a number of Federal and State/Territory **home-based and community care** programs. Most notable is the **Home and Community Care (HACC)** Program, whose services - in order of magnitude - include centre-based services, domestic assistance (home help with cooking/meals, cleaning, errands, transport, home maintenance and modifications), personal care, social support, home nursing and respite care (in-home respite is growing in popularity as the dislocation of day centre care can exacerbate disorientation for the person with dementia). HACC provided 25.3 million hours of service to some 583,000 people including delivery of 8.4 million home meals in FY2001-02. The average age of HACC clients is 71.6 years, 66% are female, 93% are pensioners and 52% have a carer available to assist them. *Up to one in five HACC clients may have some form of dementia.*

**Community Options Projects (COPs)** provide case management and individually designed service packages, of which about 16% are for people with dementia. **Community Aged Care Packages (CACPs)** were introduced in 1992, where a case manager provides a package of services to enable the client to continue to live in the community. Of the 24,100 people who receive CACPs, 26% have mild dementia and a further 9% have moderate to severe dementia.<sup>56</sup> These are like low level residential

<sup>55</sup> See [www.agedcare.org.au/factsheets/factsheet3\\_communitycare.htm](http://www.agedcare.org.au/factsheets/factsheet3_communitycare.htm)

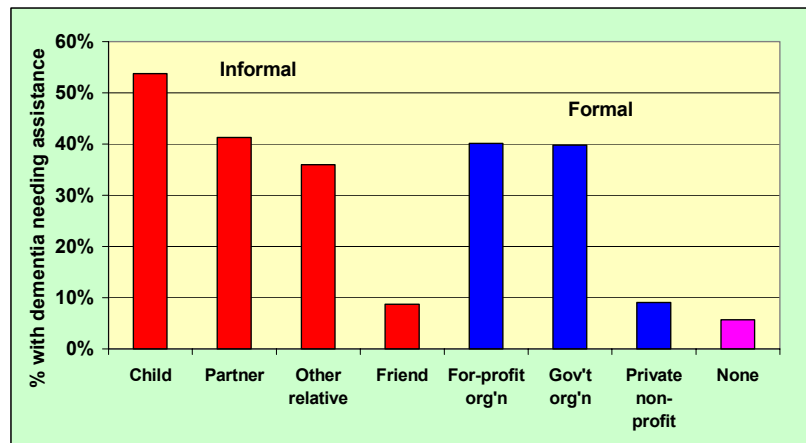
<sup>56</sup> Data sources, also for HACC figures are AIHW (2002a) and DHA (2002a). The latter also states that ‘up to 5% of existing low level residential care places may be converted to CACPs’. 1,150 new CACPs were released in 2002.

care, but in the home, and are growing rapidly and also emphasising dementia. **Extended Aged Care in the Home (EACH)** packages commenced in 1998, and are like high level care in the home and, following trials, were granted additional extension funding in 2001-02 and 2002-03 Budgets. Other Federal programs (some delivered through or in conjunction with Alzheimer’s organisations, see Section 1.2.5 on Peak Community Bodies); include:

- DESP - the Dementia Education and Support Program (\$1.4m budget), including a helpline;
- the Carer Information and Support Program (\$2m), for all carers;
- NRCP - the National Respite for Carers Program (\$87.6m), including over 100 community respite services for families and carers of people with dementia, plus three education and support programs:
  - CEWT - the Carer Education and Workforce Training Project (\$1.1m)
  - the Early Stage Dementia Support and Respite Project (\$1.5m)
  - NDBAS - the National Dementia Behaviour Advisory Service (\$0.4m)
- PGUs - Psycho-geriatric Care Units (\$3.5m), with States; and
- Dementia Support for Assessment Program (\$1.1m): rural and remote assessment and counselling.

Although fees are charged for community services, inability to pay does not preclude access. However, because demand outstrips supply, waiting lists are becoming problematic. More funding is required to relieve the supply constraints in services that are provided through the formal sector.

**Chart 2: Informal and formal caregivers for people with dementia in households**



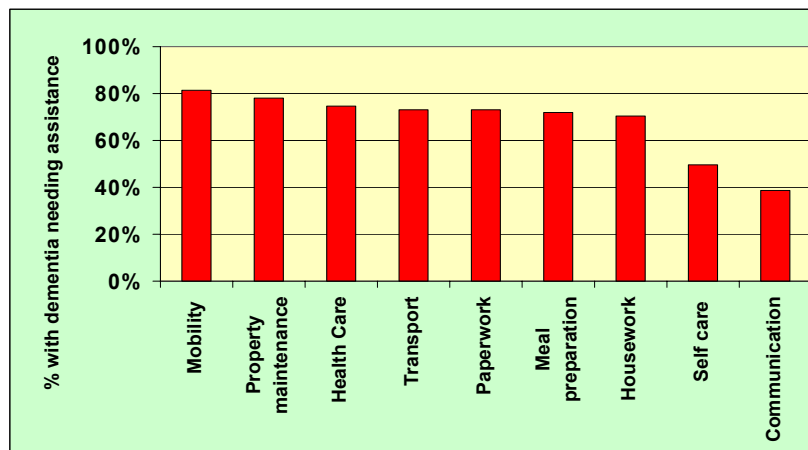
Source: Access Economics based on ABS special data request, 1998.

Care from the informal sector, however, still exceeds that provided through programs. Chart 2 shows the proportion of people with dementia in Australian households who need assistance, who have carers of various types in both sectors (the percentages are not additive). Over half have a child as a carer, while around 40% depend on a partner, on a for-profit organisation and on government. Around 5% report having their care needs unmet.

Chart 3 shows the proportion of people with dementia in Australian households who need assistance, by the area of the need as supplied by the informal and formal sectors (again the percentages are not additive). Mobility assistance is the greatest need, required by over 80% of people, although the requirement for assistance with property maintenance, health care, transport paperwork, meal preparation and housework are also very high (required by over 70% of people needing assistance).



**Chart 3: Informal and formal types of care for people with dementia in households**



Source: Access Economics based on ABS special data request, 1998.

### 1.2.9 Residential Care

Even with the provision of the best home services, for most people there comes a time when the **transition to residential care** is deemed appropriate. Entry into residential care is better predicted by carer factors than by patient factors, possibility precipitated by an adverse event (eg, an accident or illness) or by carer burnout. It can be a difficult time for the individual and the carer(s), in terms of confronting the terminal nature of dementia as well as the grief and other emotional and family upheavals that often transpire. Relinquishing full time care of a loved partner of many decades can be traumatic, with mixed feelings of not being able to continue any longer, together with feelings of desolation, guilt or failure and thoughts that the marriage is over (didn't their vow say "in sickness and in health?"), that they have deserted or been deserted by their spouse without consent or that they will be perceived to be abandoning them, and fears that either they or their loved one will be unhappy, uncared for, lonely or alone. The family (particularly in some cultures) may not agree about the decision to place the loved one in care, the timing of the move, or the particular accommodation, which can cause family stress.

As well as the emotional distress of placing a loved one in residential care, there are also well-documented problems in gaining access to appropriate residential accommodation (see Section 3.2), and another key issue at the time of transition to residential accommodation is frequently money. Weekly fees are means tested and limited to a proportion (85%) of the single age pension rate plus any income tested fee, and 16-40% of places must be for concessional residents, depending on the region. However, there may be extra fees for certain therapies and the family home may need to be sold to pay for up-front costs (notably accommodation bonds), particularly if the desired accommodation provider is an Extra Services Provider (ESP).<sup>57</sup> Many families and carers (partners or children), seek levels of quality care that can be very financially challenging, either because they are unaware of the full costs, or they feel bereft or guilty for placing their loved one in care, or simply because they want really good quality care for their loved one. Prudential protection (insurance) for the charges and bonds, either through Medicare or private health insurance (PHI), might help to alleviate problems that sometimes arise in this regard.

There are two major divisions of residential care – **low care facilities (formerly called hostels) and high care facilities (nursing homes)**. High care facilities focus on the provision of continuous,

<sup>57</sup> A maximum of 12% of places may be extra services places.

intensive nursing care, while low-care facilities focus on personal rather than nursing services and accommodate less impaired residents.

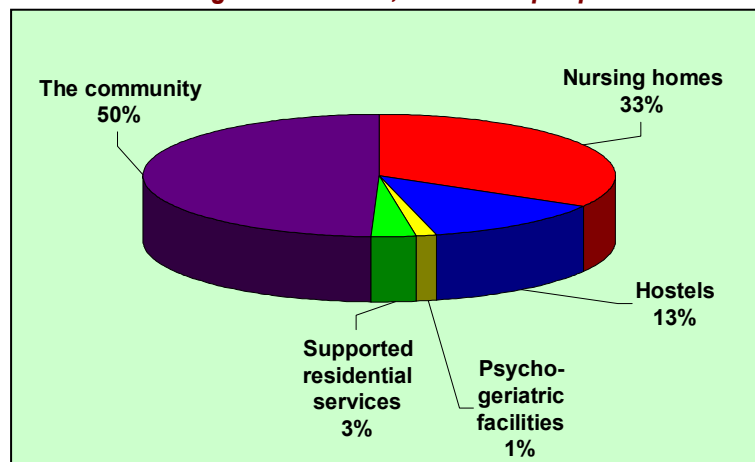
*For some families, great leaps must be made to accept the idea of changing from home help to residential care, and from hostel to nursing home care. Hostels provide downsized independent living; they are homes away from home. They may offer comfy armchairs, bridge games and shopping expeditions. A nursing home is more hospital-like, perhaps with grey lino, crocheted rugs and walking frames. Hostels lie somewhere between a retirement village and a nursing home. Some complexes provide all three levels of care... The quality of hostel accommodation ranges from Spartan to five-star.*  
 Hampson (2000), p223.

Residents with dementia may be supported in either:

- *mainstream* facilities, where residents with dementia and those without (frail aged) are integrated, with no separate, locked or partitioned areas;
- *separated* accommodation, where separation is achieved via dementia-specific wings attached to a mainstream facility (with little or no contact with frail aged residents), dementia-specific units co-located on the same site as a mainstream facility, or in stand-alone dementia-specific facilities (operating quite independently).

A small proportion of people with dementia are accommodated in psychiatric hospitals and, increasingly, psycho-geriatric units. Chart 4, based on Gibson et al (1999) shows the distribution of people with dementia in various care settings – half in the community, one third in nursing homes, one in eight in hostels and 4% in other facilities.

**Chart 4: Care settings in Australia, % of total people with dementia**



Source: Access Economics based on 1996 data from Gibson et al (1999).

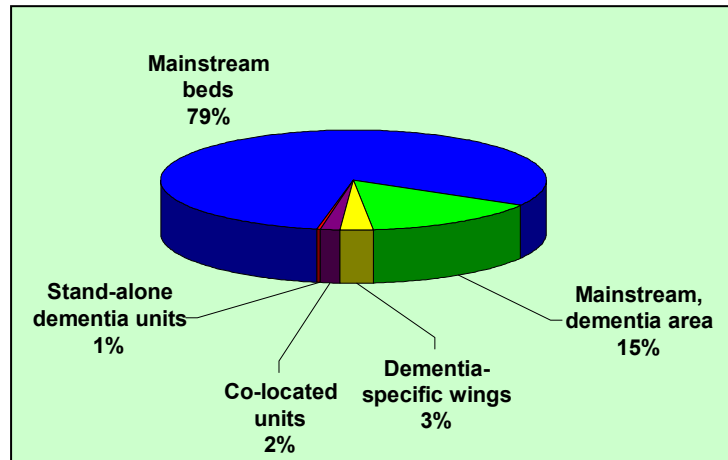
There are currently 144,100 residential care places in Australia, of which 6,300 were released in January 2002. The occupancy rate is 97% and the average age of residents is 83.2 years. About 64% of high level care residents enter from hospital, 26% from low level care and 10% direct from the community. ALOS is 36 months with 35% staying less than 1 year and 22% staying more than 5 years.

**Dementia-specific care:** At least 60% of Australia’s nursing home residents and 30% of our hostel residents have dementia. Moreover, more than 90% and 54% respectively have an obvious cognitive impairment (Rosewarne, 1997).<sup>58</sup> Chart 5 shows the distribution of residential services, with mainstream nursing home beds dominant (nearly four in five beds). Moreover, dementia areas in mainstream

<sup>58</sup> Levels of cognitive impairment for those in nursing homes were 10% none, 22% mild, 27% moderate and 41% severe, while for hostel residents they were 46% none, 35% mild, 17% moderate and 3% severe.

facilities account for another 15% of beds. Overall, however, only 5% of hostel and 6% of nursing home beds are dementia-specific - mainly wings and co-located units.

**Chart 5: Types of residential care services for people with dementia in Australia**



Source: Access Economics based on 1996 data from Gibson et al (1999).

Table 1 summarises care settings for people with dementia in Australia in 1996, based on Rosewarne et al (2000). This shows a slight fall since 1996 in the relative number of Commonwealth-funded high care places, reducing the proportion of residential care in the total from 50% to 47.9%.

**Table 1: Living arrangements for people with dementia, Australia, 1999**

	Commonwealth		State	Private	Total living in		All persons
	Low care	High care	Psycho-geriatric facilities	Supported residential services	Residential care	The community	
<b>Number</b>	18,268	45,000	2,000	4,000	69,268	75,260	144,528
<b>Per cent</b>	12.6%	31.1%	1.4%	2.8%	47.9%	52.1%	100.0%
	<b>Dementia-specific beds</b>				<b>Mainstream beds</b>		
	<b>Wings</b>	<b>Co-located units</b>	<b>Stand-alone units</b>	<b>Total</b>	<b>Mainstream only</b>	<b>Mainstream with a dementia area</b>	<b>Total</b>
<b>Low-care</b>							
<b>Number</b>	1,696	1,044	392	3,132	52,263	9,851	65,246
<b>Per cent</b>	2.6%	1.6%	0.6%	4.8%	80.1%	15.1%	100.0%
<b>Hi-care</b>							
<b>Number</b>	2,625	875	825	4,325	61,232	9,356	74,913
<b>Per cent</b>	3.5%	1.2%	1.1%	5.8%	81.7%	12.5%	100.0%

Source: Rosewarne et al (2000).

Dementia specific residential facilities have been very positive developments in the last two decades of aged care in Australia. In the mid-1980s, large suburban houses were renovated and adapted, and early models emerged such as Aldersgate Village in South Australia and the CADE units of the NSW Department of Health. In the 1990s, many ‘homely’ dementia facilities sprung up, provided by Anglican Homes, Hammond Care, Frontier Services, Catholic Health providers and others. Capital costs were higher (due to single rooms, ensuites), but the capacity to charge entry loans for most residents addressed this issue. Ongoing staff costs, however, were a real problem, to which the Commonwealth Government responded with the Aged Care Act (1997) and single Resident Classification Scale across hostels and nursing homes. However, the decision later in 1997 (policy on the run) that no accommodation bonds would be charged to nursing home residents is substantially reducing the incentives to invest in dementia specific care (see Section 3.2.2).

### 1.3 PREVALENCE

#### 1.3.1 Worldwide prevalence

As age advances, the risk of developing dementia rises sharply. Worldwide, the frequency of AD among 60-year-olds is about 1% after which the prevalence doubles about every 5 years, to around 2% at age 65, 4% at 70, 8% at 75, 16% at 80, and 32% at 85. It is estimated that as many as two-thirds of those in their nineties suffer from some form of dementia.<sup>59</sup> Table 2 shows the rising prevalence of dementia by age-group over 60, for different continents, based on meta-studies to date.<sup>60</sup>

**Table 2: Prevalence of dementia by age and continent**

Age group	Europe	North America	Asia	Africa
60-64	0.4 – 1.0	0.2 – 0.3	0.3	
65-69	0.9 – 1.4	0.8 – 0.9	1.0 – 2.4	
70-74	2.1 – 4.1	1.3 – 2.0	1.5 – 7.0	0.9
75-79	4.6 – 14.6	3.6 – 6.3	10.8 – 15.1	
80-84	9.6 – 27	8.9 – 12.7	16.3 – 38.9	0.7
85-89	20.4 – 38.3	16.3 – 29.7		
90-94	28.3 – 57.3	40.4 – 74.3		9.6
95+	42.3 – 55.8	58.6		

Source: Wimo et al (1998), p14.

Prevalence is thus very dependent on the age structure of the population. Alzheimer's Disease International (ADI) reports that in the year 2000 there were 18 million people in the world with dementia compared with 11 million in 1980. By 2025 ADI projects there will be 34 million with dementia of whom 25 million (71% of the total) will live in the developing world. Because developing countries are not so far along in their demographic transition, by 2025, there will be twice as many people with dementia in the developed world as in 1980, but there will be *four* times as many people with dementia in the developing world.<sup>61</sup> Where does Australia fit, now and in future?

#### 1.3.2 Current prevalence in Australia

Table 3 shows the national estimated prevalence of diagnosed dementia in 2002, by demographic cohort. The actual level (including a significant number of mild to moderate cases not diagnosed) is likely to be much higher (see Methodology). It is noteworthy that current life expectancy at age 65 for women is now 85 years, and for men is 82 years, and increasing.

Over 162,000  
Australians in 2002  
have diagnosed  
dementia, 0.8% of  
the population.

**Table 3: Prevalence of dementia in Australia, by age and gender, 2002 and 1993**

Age group	Males 2002		Females 2002		Total 2002		Total 1993
	'000	%	'000	%	'000	%	%
0-24	-	-	-	-	-	-	-
25-64	4.3	0.2%	2.3	0.1%	6.6	0.1%	0.1%
65-74	12.1	1.9%	7.6	1.1%	19.7	1.5%	1.2%
75-84	20.7	5.7%	34.1	6.8%	54.8	6.3%	6.0%
85+	19.1	22.8%	62.0	33.6%	81.1	30.2%	23.4%
Total	56.3	0.6%	106.0	1.1%	162.3	0.8%	0.6%

Source: Access Economics, based on ABS special data request and international meta-analyses (see Methodology). Note standard error may be relatively higher for the 25-64 age groups. Prevalence under age 24 was not statistically significant.

<sup>59</sup> Life Extension Foundation (2002).

<sup>60</sup> Differences between continents are due to methodological differences between studies, possible ethnic variations, variation in diagnostic criteria, different survival rates and different geographical distribution of vascular risk factors.

<sup>61</sup> ADI website.

Table 3 shows that in 2002 there were 162,300 Australians with diagnosed dementia of whom over 106,000 were women. Half of those with dementia were 85 years of age or older, and a further third were 75 to 84 years. Of those 75 or older, prevalence rates were higher for women than men, while in younger age groups, prevalence was slightly higher amongst males. The higher prevalence for women in the age group over 85 years is partly attributable to the greater longevity of women who survive to an age where the likelihood of dementia becomes extremely high. Similarly, in the 75-84 age group, the distribution for men is likely to be skewed more to the younger end than it is for women.

A comparison with the 1993 data, derived using the same methodology, is also of note, as the prevalence has increased in all cohorts. This is partly due to increased longevity (particularly in the oldest cohorts) as well as increase in diagnosis (across the spectrum) over the past decade.

Another key issue is the significant number of younger people who have dementia, 6,600 in 2002 aged under 65 (see Table 3). The impact on younger people can be even greater as they may be more financially exposed and have more children, family and career responsibilities. The services they need, from diagnosis to residential care, are likely to be difficult to get or unavailable – because dementia care is still bound to aged care (Freeth, 1994).

A final point is in relation to indigenous Australians. Because fewer Aboriginal and Torres Strait Islander people reach old age, there are fewer cases of dementia in these communities, in absolute numbers. However, the age-adjusted prevalence of dementia may in fact be higher in these communities than in the Australian population as a whole – one study showed as many as 10% of indigenous people over 65 diagnosed with dementia, and another 10% with suspected dementia. Alcohol abuse and cerebrovascular disease were found to be important causes of dementia, which are largely preventable (Henderson and Jorm, 1998; Pollit 1997).<sup>62</sup>

**1.3.3 Projected prevalence in Australia**

Prevalence of dementia is forecast to grow rapidly over the coming decades due to population ageing. The projections in Chart 5 are based on ageing alone. There is downside risk if new treatments, including pharmaceutical therapies and lifestyle changes, prevent or postpone dementia.

Over 580,000 Australians will have dementia by mid-century, 2.3% of the population.

**Chart 6 : Projections of dementia prevalence and population growth, Australia, 2002-2051**

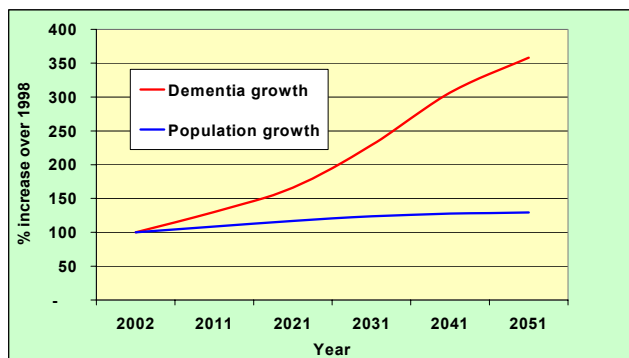


Chart 6 shows projections of the prevalence of dementia to 2051. By mid-century, the Australian population is forecast by the ABS to increase by 36%. The prevalence of dementia, however, based on current prevalence rates by demographic cohort, will increase nearly fourfold, to 581,300 people. Prevalence will reach the half-million mark around 2041.

Source: Access Economics projections.

<sup>62</sup> 1% of people in residential care are indigenous Australians.



## 1.4 HEALTH AND SOCIOECONOMIC IMPACTS IN AUSTRALIA

### 1.4.1 Disability

The disability burden of dementia is severe – 98.5% of people with dementia are classified as disabled compared with 19.3% of all Australians according to the definitions of disability in the 1998 ABS Survey of Disability, Ageing and Carers (see Methodology Section). Moreover, as Table 4 shows, 99.8% of those with dementia who are disabled have specific restrictions, compared with 87.4% of disabled people generally. Even more telling, 94% of people with dementia who have restrictions are classified as having “profound” core activity restrictions, compared with the average of 19%.

**Table 4: Disability associated with dementia**

	People with core activity# restrictions					All with specific restrictions*	All with disability
	Profound	Severe	Moderate	Mild	Total		
<b>People ('000)</b>							
<i>Dementia</i>	60	4	0	0	64	64	64
Subtotal mental/behavioural	158	92	53	93	396	480	529
Subtotal physical	380	506	608	939	2,433	2,676	3,081
Total with a disability	538	598	660	1,032	2,828	3,156	3,610
<b>% of total**</b>							
<i>Dementia</i>	93.9%	6.0%	0.0%	0.2%	100.0%	99.8%	
Subtotal mental/behavioural	39.8%	23.3%	13.3%	23.6%	100.0%	90.6%	
Subtotal physical	15.6%	20.8%	25.0%	38.6%	100.0%	86.9%	
Total with a disability	19.0%	21.2%	23.3%	36.5%	100.0%	87.4%	

#Core activities comprise communication, mobility and self-care. \* Includes schooling and employment restrictions. \*\* First five columns are relative to the total number of people with core activity restrictions; sixth column is relative to all those with a disability. Source: Access Economics, derived from ABS (1999), Table 10 for 1998.

### 1.4.2 Socio-economic status and rurality

People with dementia tend to have lower incomes. Over 70% of people with dementia have income in the lowest two quintiles – that is, compared with the lowest 40% of the general population (Table 5). The distribution between those in capital cities and those in rural and remote areas, however, is roughly similar (Table 6).

**Table 5: Income of people with dementia**

Income quintile	% with dementia in quintile
Lowest 20%	6.0%
Second 20%	64.2%
Third 20%	23.1%
Fourth 20%	5.3%
Highest 20%	1.5%
Total	100.0%

Source: Access Economics based on ABS special data request, 1998.

**Table 6: Urban-rural distribution of people with dementia**

	% with dementia	% of total
Capital city	62.8%	63.9%
Balance of State	37.2%	36.1%
Total	100.0%	100.0%

Source: Access Economics based on ABS special data request, 1998.

**1.4.3 Employment**

People who have dementia are under-represented in Australian employment. Table 7 shows that only 2.3% of those aged over 65 who have dementia are employed, compared to 8.5% of the population as a whole. The sample of those employed with dementia was too small to permit a statistically significant subset to establish absenteeism rates relative to the population as a whole. It is more possible to remain employed for a time if the illness is in the early stages, if the work environment is supportive, if tasks are familiar or repetitive and if supervision and occupational health and safety arrangements are adequate. Inadequacies in the latter for self-employed people may necessitate earlier retirement for them. For many employed people, workmates may be the first ones to notice changes pre-diagnosis in gradual onset cases of dementia.

**Table 7: Proportion of people aged 65+ employed, with dementia and total**

	All Australians	Australians with dementia
Employed	8.5%	2.3%
Not employed*	91.5%	97.7%
Total	100.0%	100.0%

\* Includes those not in the workforce and those looking for work.  
 Source: Access Economics, based on ABS special data request, 1998.

*Christine Boden was 46 years old when diagnosed with younger onset AD, formerly a federal government senior executive. She writes: “After the final diagnosis by the second specialist in mid-September 1995, I faced the task of seeking retirement on medical grounds... My battles with the superannuation company epitomise the misunderstanding about Alzheimer’s as a killer disease... The suggestion that I return to work for retraining [in a lower level job] appalled all the medical people associated with my case, as well as my department and ... the Alzheimer’s Association. We all knew at least the basics of Alzheimer’s: that the first capacity to be lost is holding a job and that, in particular, learning any new tasks is almost impossible for someone with the disease. And here was the suggestion that I should not only continue to try to hold a job, but learn a completely new one, with a whole range of new tasks, new places to find, new colleagues to recognise! ... It would mean driving through heavy traffic... remembering a whole list of issues, learning (or rather coping with the embarrassment of never remembering) so many new things. I became very distressed... with continual migraines again, and rapidly increasing confusion... The specialist warned that stress would exacerbate the progress of the disease.” Four months later, when the board agreed to retire Christine, she was “speechless with relief”.*

Boden (1998), p41-44.

**1.4.4 Use of medical services**

People with dementia go to the doctor more frequently than the average Australian, and also more than others their own age. Table 8 reflects that 36.6% of those with dementia visit their GP in a fortnight, significantly more than the average for all Australians of 21.0%, and slightly more than those over 65 (35.6%). For specialist visits, the difference is even more pronounced, with more than double the proportion of those with dementia (9.2%) visiting a specialist in a representative fortnight compared to the average 4.1% of Australians, and a third as much again as the average of those their own age.

**Table 8: Proportion of people with dementia visiting the doctor, 1998**

	People with dementia	All Australians	Australians over 65
Visited GP in last 2 weeks	36.6%	21.0%	35.6%
Visited medical specialist in last 2 weeks	9.2%	4.1%	6.9%

Source: Access Economics, based on ABS special data request and ABS (1997), Table 14 for last two columns.

Epidemiological studies have confirmed the higher utilisation of health services, and hence higher direct health costs, of people with dementia compared to those without, adjusted for age, gender, location and co-morbidity. Gutterman et al (1999) found that:

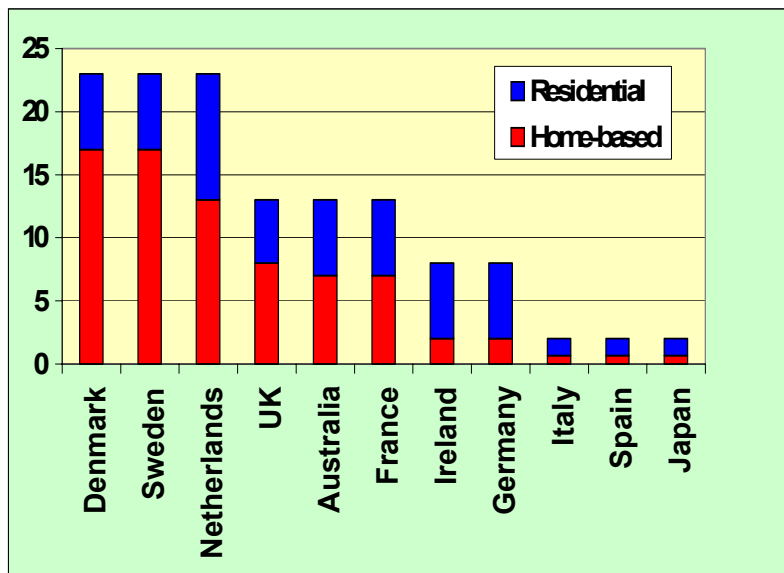
- hospital stays were twice as long on average and emergency department costs 2.5 times greater;
- hospital, medical and pharmaceutical costs were 1.5 times higher (not including nursing home costs), although pharmaceutical costs and outpatient costs were not significantly different;
- 75% of the disparity was linked to greater inpatient care.

**1.5 INTERNATIONAL COMPARISONS**

The dementia epidemic is worldwide. In demographic terms, Australia is quite “young” among developed nations – the “oldest” countries being in Europe and, particularly Scandinavia where although the proportion of those aged 65 is already over 15%, the growth of this age-group is stabilising (below 1%). In comparison, Australia, with only 12.5% of the population over 65, has the 65+ cohort growing at 1.8% p.a. and the 85+ cohort growing at 4.6% p.a., as our longevity is one of the highest in the world. Thus, Australia’s demographic transition is occurring relatively markedly.

“While Australia is relatively young in an international context, it is experiencing a comparatively rapid rate of population ageing.”  
*Gibson et al (1999)*

**Chart 7: People over 65 receiving home-based services and residential care, internationally**



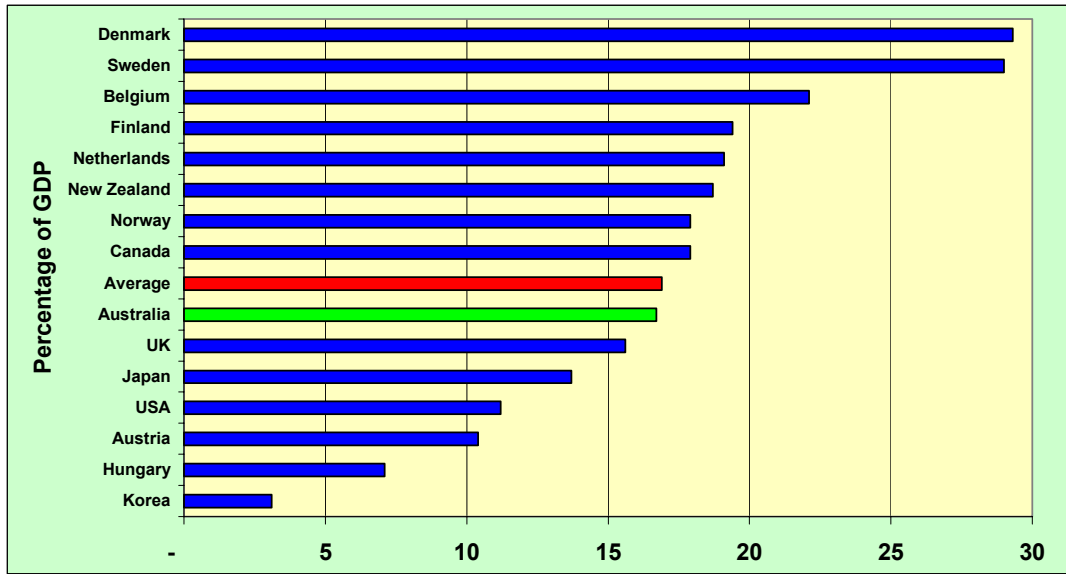
Source: Gibson, Benham and Racic (1999) for the year 1995.

The projected rapid growth of dementia prevalence depicted in Chart 6 is occurring throughout the western world. However, the extent or type of care provided is not closely related to the stage of

demographic transition, as Chart 7 shows, although the Nordics still lead the way. The levels and mix of home-based and residential care services provided varies greatly, with Australia in the middle of the range.

The proportion of national income spent on public programs for the aged is slightly more strongly correlated with the stage of demographic transition, as shown in Chart 8. For a “young” country, Australia is spending close to the OECD average on the health and long-term care for the aged, aged pensions, early retirement and other expenditure for the aged.

**Chart 8: Age-related expenditure, % of GDP by OECD country, 2000**



Source: Access Economics derived from appendix data in AIHW (2002a), Table A4.2.

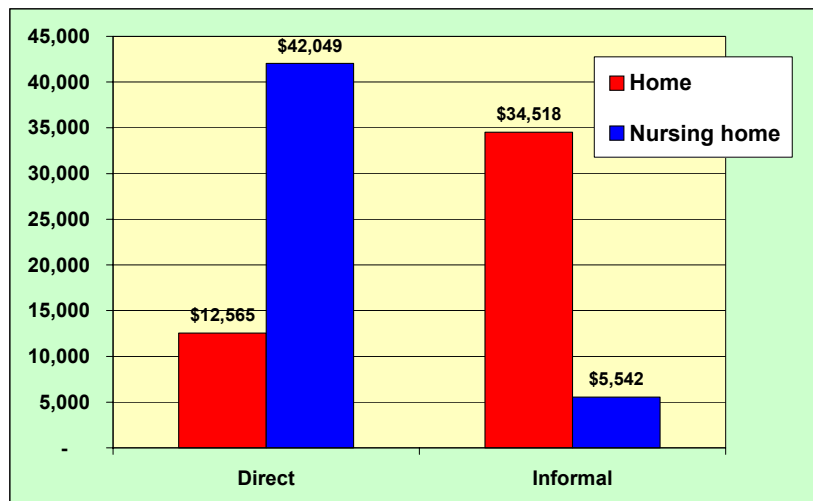
### 1.5.1 North America

In the US, the number of people with AD is forecast to increase from 4 million in 2002 to 14 million by mid-century. Dementia care costs are also increasing rapidly, with the total direct and indirect cost of AD alone estimated to exceed US\$100 billion each year – US\$25,000 per person with dementia on average.

This figure includes care expenses and lost earnings both of the person and family members.<sup>63</sup> More than 70% of people with AD in the US live at home and almost 75% of the home care is provided by family and friends (valued at US\$34,518 pa in 1990 by Rice et al, 1993 – see Chart 9). The remainder is formal sector care costing an average of US\$12,565 per year, which families pay almost entirely out-of-pocket (neither Medicare nor most private health insurance covers the long-term care most people need). Half of all nursing home residents in the US suffer from dementia. The average cost for nursing home care is US\$42,049 per year but can exceed US\$70,000 per year in some areas of the country. The person or their family provide a further US\$5,542 in additional goods and services while the resident is in care. Leon et al (1998) showed annual costs of caring for a person with mild, moderate or severe AD to be US\$18,408, US\$30,096 and US\$36,132 respectively, with 21% of the total costs being for informal care (half the Rice proportion). The average lifetime cost per person was estimated as US\$174,000 in 1991, including US\$47,581 in direct costs. Spending on AD research was US\$600million in FY2002.

<sup>63</sup> Alzheimer’s Association of the United States, [www.alz.org](http://www.alz.org)

**Chart 9: Cost of dementia care per person, United States**



Source: Rice et al 1990 study reported in Wimo et al (1998) p200.

A summary of cost of illness studies in the US is provided by Max in Wimo et al (1998, p200). Even the data above shows there is some divergence in US cost estimates, which range from US\$20,000 to US\$25,000 per person<sup>64</sup> per annum (around A\$40,000 to A\$50,000 at 2002 exchange rates).

Two recent studies that have looked at costs of informal care and to business are described below:

1. A large 2001 University of Michigan study estimates that informal care costs for dementia in the US are \$18 billion a year, based on observations of families and carers of over 7000 Americans aged 70 or more, 10% of whom showed cognitive impairment consistent with dementia (43% mild, 27% moderate and 30% severe). Time spent on assistance with ADL - dressing, bathing, eating and so on - increased from 4.6 hours (no dementia) through 8.5 hours a week extra (mild) to 41.5 hours extra with severe dementia. Time spent managing the BPSSD was not included. The hours of care given was multiplied by the average weekly wage of a home health aide. Most of the care burden was found to be borne by elderly spouses.<sup>65</sup>
2. The second study, of the cost of dementia to US businesses, showed an estimated \$61 billion spent on AD, which had doubled between 1998 and 2002 (Alzheimer's Association US, 2002b). The cost breakdowns show costs of health care at 40% (\$24.6bn) and carer costs at 60% (\$36.5bn), including productivity losses (30%, \$18bn,) absenteeism (17%, \$10bn), worker replacement costs (10%, \$6bn) and continuing insurances and temporary replacements (3%, \$2bn).

The prevalence of dementia in Canadians aged 65 and over has been estimated at 8% (5% with AD), amounting to over 250,000 people. Projections indicate that by 2021, there will be almost 600,000 Canadian seniors with dementia, increasing to 778,000 in 2031. As in Australia, half of those with dementia live in the community and half are institutionalised; with the former generally with less severe forms of dementia.

<sup>64</sup> Using the data above, 75% (3m people) live at home costing \$12,500 per person = 37.5bn plus 1m at \$42,000 each = US\$79.5bn, suggesting US\$20,000 per person for 4m people. Alternatively, lifetime costs of \$174,000 with average life expectancy of eight years suggest average cost of US\$21,750 per person. \$100bn in total with 4m people suggests average costs of US\$25,000 per person.

<sup>65</sup> Dr Susan Aldridge, *The cost of dementia*, on [www.healthandage.com](http://www.healthandage.com). For the full article, see *Journal of General Internal Medicine*, November 2001. These care hours may be quite conservative – a 1985 US study showed the average care hours for mild and moderate dementia to be 22 and for severe dementia to be 56. An Italian study showed 45 hours of personal care required and 18 hours of other non-medical services (Lowin et al, 2000).



In a 1991 study by the Canadian Study of Health and Aging (CSHA) published in the November, 1994 issue of the *Canadian Medical Association Journal*, annual net costs for people 65 years of age and older were very conservatively estimated at \$3.5 billion (A\$3.9 billion), or about C\$14,000 (A\$15,575) per person with dementia per year.<sup>66</sup> The total figure comprised community costs of almost \$1.3 billion (33%), costs to long term institutions of almost \$2.2 billion (56%), drug costs of \$60.6 million (1.6%) and diagnostic costs of \$13.5 million (0.3%). The total annual net costs for people under age 65 were \$389.2 million. Dementia was estimated to be 4.9% of health costs in 1991 but 5.8% by 1994. Net average cost of community care for moderate and severe patients was 2.27 times more than for mild patients. Research for both groups accounted for only \$9.8 million – A\$10.9m.<sup>67</sup>

### 1.5.2 Europe

In the UK, over 700,000 people have dementia, with prevalence of 1 person in 120, estimated as 1 in 1000 for people aged 40-65, 1 in 50 for people aged 65-70, 1 in 20 for people aged 70-80 and 1 in 5 for people over 80.<sup>68</sup> There are 18,500 people under the age of 65 in the UK who have dementia, with the prevalence between 30 and 60 years of age 67.2 per 100,000.<sup>69</sup> AD is estimated to cause 55% of dementia, vascular dementia 20%, dementia with Lewy bodies 15%, fronto-temporal dementia 5% and other forms 5%. By 2010 there will be about 840,000 people with dementia in the UK, expected to rise to over 1.5 million by 2050.<sup>70</sup>

The annual cost of dementia in the UK was estimated in the 1993 to be between £5.4bn and £5.8bn. Of this, £1bn were *direct* health and social services costs to the public sector. The direct cost of younger people with dementia was estimated at £132 million per year.<sup>71</sup> By 2000, cost estimates of AD in the UK had increased to between £7.1 billion and £14.9 billion (A\$20.2 billion to A\$42.8 billion) or A\$44,473 per person on average<sup>72</sup>, excluding costs of mortality and lost productivity. The NHS and local authorities pay for about 42% of *total* costs, the rest being borne by the Department of Social Security or people with dementia and their families. Costs of formal care are dominated by institutional care, particularly in hospitals and nursing homes where one estimate puts the full costs of care at £278.86 per week for mild to moderate illness (A\$41,625p.a.) and £338.38 per week (A\$50,510 p.a.) for severe illness; while the person is at home, informal care costs are typically much larger than the paid cost of formal care. Costs are estimated to increase to £10.7bn to £20.7bn by 2021. Research costs are only £5.6m per annum for AD (Lowin et al, 2000).

O'Shea (2000) showed the costs of caring for a patient with AD in Ireland in 1996 were £328m to £453m or between £10,933 and £15,100 per person per annum, equivalent to A\$31,385 and A\$43,345 respectively. He notes that these estimates "come at the lower range of published estimates in the international literature". The division of costs in this study (for the lower end of the spectrum) was: carer costs £154m (47%), residential care £82 (25%), GPs and community care £16 (5%), psychiatric hospitals £14m (4.3%), acute hospitals £5m (1.5%), and other costs £57m (17%).

<sup>66</sup> Østbye T and Crosse E (1994) "Net economic costs of dementia in Canada" *Can Med Assoc J* 1994;151(10):1457-64.

<sup>67</sup> Larry Segel *The Underwriting Edge*, on [www.marketingoptions.com/c\\_Is124.htm](http://www.marketingoptions.com/c_Is124.htm).

<sup>68</sup> Bosanquet, May, Johnson (1998) "Alzheimer's Disease in the United Kingdom - Burden of Disease and Future Care".

<sup>69</sup> Harvey, (1998) "Young Onset Dementia: Epidemiology, clinical symptoms, family burden, support and outcome" 1998.

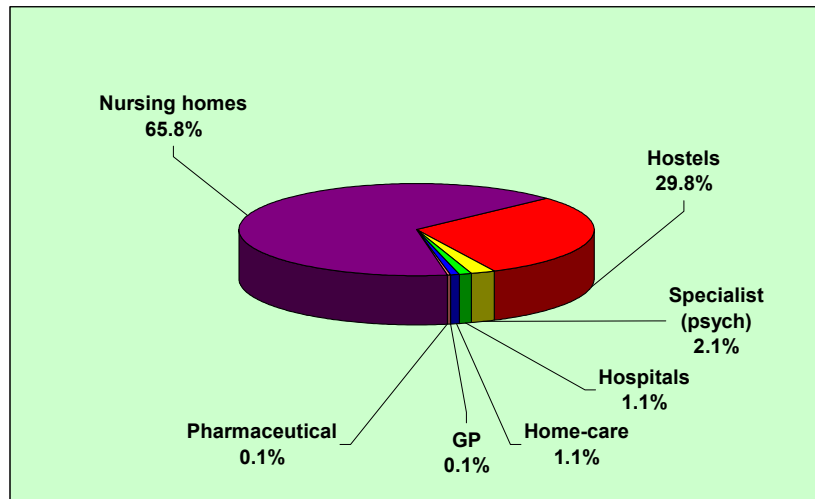
<sup>70</sup> The Alzheimer's Society web site, [www.alzheimers.org.uk](http://www.alzheimers.org.uk).

<sup>71</sup> Bosanquet et al (1998) *ibid* and Harvey (1998), *ibid*. Also Alzheimer's Europe (2002) for the cost per person.

<sup>72</sup> Lowin, McCrone and Knapp (2000) "Cost of Alzheimer's Disease and Level of Research Funding". Souetre et al (1999) estimated the total cost per patient over three months as an enormous £6,616 (mild), £10,250 (moderate), and £13,593 (severe) – equating to A\$75,966, A\$117,693 and A\$156,078 per person with dementia p.a. respectively!

Costs of dementia in other European countries range considerably, from 19% of total health care costs in Sweden, by far the highest, to around 5.6% in the Netherlands (close to the average). Chart 10 shows the Dutch direct health costs predictably dominated by nursing homes (around two thirds of direct costs), followed by hostels (30%), with specialist psychiatric services, hospital costs, home-care, GPs and pharmaceuticals together accounting for less than 5% of total health system costs.

**Chart 10: Costs of Dementia in the Netherlands**



Source: Access Economics derived from Koopmanschap et al in Wimo et al (1998).

In terms of per capita expenditures in Europe, studies in France and Germany show direct costs in the order of US\$6,778 and US\$11,661 respectively for 1991 and 1995, although different methodologies and variable exchange rates make close comparisons of these low estimates difficult. Costs in Europe are projected to grow on average in real terms by around 1.9% p.a. for 1985-2020 and 2.6% p.a. for 2020-2040 (Koopmanschap et al in Wimo et al, 1998).

Perhaps the most frightening statistic in recent research in Europe was that 41.8% of people diagnosed with AD did not receive further information on the disease or on existing services and treatment.<sup>73</sup>

Within this international context, we now turn to cost estimates for Australia.

## 1.6 SUMMARY OF CHAPTER ONE

Dementia is a disabling organic brain syndrome characterised by progression from mild, through moderate, to severe illness, with death after an average of eight years. **Symptoms** include loss of cognitive abilities, behavioural and psychological symptoms, and functional disability. **Diagnosis** can be complex. There are many diseases that cause dementia with varying symptoms and progression, the most common being Alzheimer's disease (AD), vascular dementia, dementia with Lewy bodies and fronto-temporal lobe dementia. The most established risk factor is age; others include family history, gender and cardiovascular risk factors, while protective factors may include use of anti-inflammatories, oestrogen and statins as well as intake of antioxidants.

**Prevention** of dementia is currently focused on postponing the onset of symptoms to later in the lifespan, increasing healthspan and potentially preventing tens of thousands of institutionalisations per annum. **Research** is promising – with the best chances for AD elimination possibly related to an

<sup>73</sup> Alzheimer Europe (2002), p1.

immune system response that destroys beta-amyloid plaques in the brain. Research is also vital to find more effective models of care for people with dementia. **Early diagnosis and intervention** are paramount, ensuring the person and the family can benefit from the many advantages of drug treatments, support and planning, which improve coping and quality of life.

**Pharmacological management** includes cholinesterase inhibitors (CEIs), which ameliorate the symptoms of illness but do not reverse disease or prolong life. Three of these – Aricept, Exelon and Reminyl – are available on the PBS for mild to moderate AD under certain conditions, including demonstrated improvement. Other pharmacotherapies can include aspirin and blood thinning agents, anti-psychotics, memantine (not yet TGA-approved) and a range of natural treatments such as Ginkgo biloba, Vitamins C and E and folic acid.

**GPs** play a key role in medical treatment – recognising, assessing, planning, managing, referring and supporting the person and their carer. However, only half of GPs are able to recognise mild dementia and more information and resourcing is required. Neurologists, psycho-geriatricians and other **specialists** also have a key role in assessing, treating and prescribing. Acute **hospital care** for people with dementia has four times the ALOS (average length of stay) of the general population. Multidisciplinary **memory clinics** are a useful, important and accepted new community solution (with specialist input) to coordinating dementia assessments and supporting the person with dementia, the family carer and the GP.

**Psychosocial interventions** are very important for disease management and quality of life, including counselling, psycho-education, understanding of behavioural and psychological symptoms of dementia (BPSD), problem-solving strategies, person-centred care, modelling and specific therapies such as physical, occupational, diversional, reminiscence, validation or music therapies. 25% of Australian older people are from non-English speaking backgrounds, requiring special consideration or services. **Community bodies**, such as Alzheimer’s Australia and Carer Associations are able to meet a wide range of community needs including information, resources, support, education, counselling, referral, legal and financial services, advocacy and program delivery. For example, Alzheimer’s Australia delivers Commonwealth-funded national programs that include the Dementia Education and Support Program (DESP), which includes the Dementia Helpline service; Carer Education and Workforce Training (CEWT); Early Stage Dementia Support and Respite Program (ESDSRP); and the National Dementia Behaviour Advisory Service (NDBAS). Private and public community support services are also available, although not equitably or comprehensively, including personal, health, accommodation and social services such as home care, adult day care and a variety of respite services.

“Ageing in place” is a fundamental element of dementia and aged care generally in Australia, where **community-based** aged care assessment teams (ACATs) assess needs and recommend appropriate care services and settings in the community or in residential care. 52% of people with dementia live in the community and are key users of services such as Home and Community Care (HACC), Community Aged Care Packages (CACPs), Extended Aged Care in the Home (EACH), psychogeriatric units (PGUs), the Carer Information and Support Program, the National Respite for Carers Program and the Dementia Support for Assessment Program. Over half of people with dementia have a child as a carer, while 41% depend on a partner and 35% on another relative. 40% use for-profit care services and 40% use government services. Greatest needs are for mobility, property maintenance, healthcare, transport, paperwork, meal preparation, housework, self-care and communication. **Informal (voluntary) families and carers** – the invisible multi-billion-dollar workforce – provide a huge contribution, which often may take a heavy toll on their own health, wellbeing and income.

As dementia progresses, and depending as much on carer as patient factors, entry to **residential care** may become appropriate – either low-care (hostel) or high care (nursing home). Quality of care remains an issue, with physical and chemical restraint still used by a majority of providers, and a long way to go in achieving widespread person-centred care strategies. Two thirds of people with dementia in residential care are in nursing homes, one quarter in hostels and 8% in psychogeriatric facilities or other supported residential services. ALOS is 3 years. Although 60% of nursing home residents and 30% of hostel residents have dementia, and over 90% and 54% respectively have an obvious cognitive impairment, 79% of residents are supported in mainstream facilities. Only 6% of beds are **dementia-specific**, with the remainder being dementia areas in mainstream facilities.

In Australia there were over **162,000 people with dementia** in 2002, including 6,600 under 65 – with ‘younger onset’ dementia. Age-standardised prevalence for indigenous people may be higher. Prevalence of dementia in older people doubles every five years from 1% at age 60, to 2% at 65, to 32% by 85 and to two thirds of those in their nineties. The prevalence of dementia is **growing rapidly** – reaching the half-million mark around 2040 and 2.3% of the population by mid-century.

The **socio-economic and disability burden** of dementia is severe – 98.5% of people with dementia are disabled. People with dementia also tend to have lower incomes, with 70% represented in the lowest two income quintiles. Rural and urban prevalence distribution is similar, although access to services is more difficult in the bush. People with dementia are under-represented in Australian **employment** – 2.3% compared to the Australian average of 8.5% for people over age 65. People with dementia also have higher than their age-average use of medical services including doctor visits and specialist visits, as well as longer hospital stays and higher age-standardised pharmaceutical costs.

The dementia epidemic is **worldwide**. As demographic ageing progresses, we witness another epidemiological transition. The management of neurodegenerative disease is the major challenge of health care systems all around the globe. Costs in the United States are estimated at between A\$40,000 and A\$50,000 per person per annum - US\$100bn in total each year. North American and European studies point to the **concentration of huge costs in residential care services** as well as on **informal family carers**, and potentially enormous cost-savings of postponing the severity of disease.

## 2. THE DEMENTIA BURDEN FOR AUSTRALIAN PEOPLE

There are three types of costs associated with dementia (see also the Methodology for this chapter):

- Direct financial costs to the Australian health system include the costs of running nursing homes and hospitals (buildings, nursing, consumables), GP and specialist services reimbursed through Medicare and private funds, the cost of pharmaceuticals (PBS and private) and of other medications, allied health services, research and “other” direct costs. The latter category includes institutional and non-institutional expenditures (such as day-care programs, home-based care and respite) and health administration. These are analysed in Section 2.1.
- Indirect financial costs (Section 2.2) tend to be borne primarily by people with dementia and those who care for them. These are dominated, in the case of dementia, by the costs of care – including the *value* of all care whether it is provided through the formal or informal (voluntary) sector. The income forfeited by people with dementia and their families and carers, due to absenteeism and early retirement, is also significant. Other costs include equipment and devices that are required to help cope with the illness, and transfer costs such as welfare and disability payments.
- Non-financial costs (Section 2.3) are also very important—the pain, suffering and premature death that result from dementia. Although more difficult to measure, these can be analysed in terms of the years of healthy life lost, both quantitatively and qualitatively, known as the “burden of disease”.

### 2.1 DIRECT HEALTH COSTS

Direct health system costs estimated in this paper are based on DCIS prevalence-based methodology developed by the Australian Institute of Health and Welfare for the year 1993-94 and currently being updated. This report extends and projects the AIHW work to estimate those costs attributable to dementia in CY2002 (see Methodology).

#### 2.1.1 Direct costs in 1993-94 and 2002

Table 9 shows the AIHW 1993-94 data, where dementia is already the most costly of mental health disorders at \$714 million, accounting for nearly one quarter of all mental health system costs in 1993-94. Spending in the ‘other direct’ category (\$582m), mainly nursing homes and hostels, dwarfs that of other mental illnesses and is still grossly under-estimated (see Methodology). Community care was separate spending under the Aged Care program budget in 1993-94.

**Table 9: Comparison of the direct health system costs of mental disorders, \$m, 1993-94**

	Hospital	Medical	Pharma- ceuticals	Other health services	Other direct	Total	% of Total
<b>Dementia</b>	<b>110</b>	<b>11</b>	<b>2</b>	<b>9</b>	<b>582</b>	<b>714</b>	<b>23.6%</b>
Affective disorders (inc. depression)	217	141	68	70	148	644	21.3%
Schizophrenia	275	26	8	106	40	454	15.0%
Substance abuse disorders	136	46	12	18	136	348	11.5%
Anxiety disorders	24	102	51	25	37	239	7.9%
Behavioural syndromes	17	53	45	9	50	174	5.8%
Other non-drug psychosis	63	5	1	6	53	128	4.2%
Stress and adjustment disorders	28	27	7	31	19	112	3.7%
Disorders of childhood and adolescence	10	9	1	19	16	55	1.8%
Other disorders, prevention & screening	61	19	3	42	29	154	5.1%
<b>Total</b>	<b>941</b>	<b>438</b>	<b>199</b>	<b>334</b>	<b>1110</b>	<b>3022</b>	<b>100.0%</b>

Source: Mathers, Vos and Stevenson(1999), p90, Table 6.6, condensed.



By 2002, the costs of dementia were estimated as \$3.2 billion, due to a 62% increase in the number of people with dementia over the period, a 37% increase in costs, and an original underestimation of the residential care component (see Methodology). The distribution of these costs across the health system is shown in Table 10.

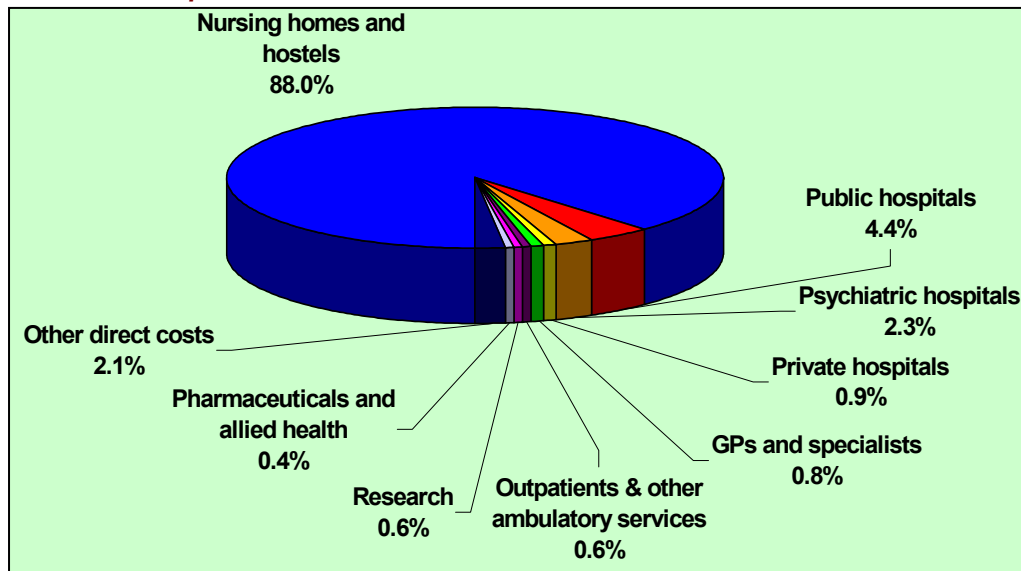
**Table 10: Components of direct health costs for dementia, 2002**

Direct health cost	\$m	% of total
Nursing homes and hostels	2,847.1	88.0%
Public hospitals	141.2	4.4%
Psychiatric hospitals	74.7	2.3%
Private hospitals	28.0	0.9%
GPs and specialists	24.5	0.8%
Outpatients & other ambulatory services	20.6	0.6%
Research	19.2	0.6%
Pharmaceuticals and allied health	13.8	0.4%
Other direct costs	66.8	2.1%
<b>Total direct</b>	<b>3,235.9</b>	<b>100.0%</b>

Source: Access Economics, based on AIHW special data request.

Chart 11 illustrates the breakdown of cost components for dementia. Residential care costs dominated the profile at \$2.8 billion (88% of the total). This represents 66% of total Commonwealth residential care subsidies in FY2002-03, estimated to be \$4.3 billion, which fits well with Rosewarne data, while not attributing all costs of people with dementia to dementia<sup>74</sup>. Second are public hospital costs at \$141m (4.4%) followed by psychiatric hospital services (\$75m or 2.3%). Private hospital services (\$28m), medical services ie, GPs and specialists (\$24.5m), outpatient and ambulatory services (\$20.6m), research (\$19.2m) and pharmaceuticals and allied health (\$13.2m) were each less than 1% of the total. Other direct costs, including health administration, were \$67m (2.1%).

**Chart 11: Components of direct health costs for dementia, 2002**



Source: Access Economics based on AIHW data.

<sup>74</sup> In Section 1.2.6 we saw that Rosewarne’s data suggests 60% and 90% of nursing home and 30% and 54% of hostel residents are effectively the minimum and maximum with dementia. Gibson’s data show that weightings for nursing homes and hostels in total residential care are 70% and 30% respectively for people with dementia (see Chart 4). The weighted averages are thus 51% and 79%, with the mean 65% of total residents having dementia. Costs per patient, however, are higher for dementia patients – hence 66% is conservative, although ballpark if an allowance is also made for those with multiple disorders. These figures conservatively concord with international data from Section 1.5.

**2.1.2 Projections of direct costs**

Section 1.3.3, particularly Chart 5, depicted the rapid growth of dementia prevalence over the coming decades. Given these demographic growth trends, together with growth in health care costs (based on trends in the Health and Community Services GDP deflator), the direct health costs of dementia are estimated to grow by 82% by 2011 (see Methodology). If we also make an allowance for increased spending on research, GPs and pharmaceuticals, then direct health costs are estimated to grow by 84% to \$6.0 billion. This ignores the potentially even faster growth of home-based aged care spending on dementia, which may need to reflect increased women’s labour force participation resulting in a reduction in “free” caregiving. Table 11 shows a breakdown of projected costs for 2011.

*The health care costs of dementia will nearly double this decade.*

**Table 11: Projected components of direct health costs for dementia, 2011**

	\$m	% total
Nursing homes and hostels	\$5,182.2	87.0%
Public hospitals	\$257.0	4.3%
Psychiatric hospitals	\$135.9	2.3%
Private hospitals	\$50.9	0.9%
GPs and specialists	\$66.8	1.1%
Outpatients & other ambulatory services	\$37.5	0.6%
Research	\$69.9	1.2%
Pharmaceuticals and allied health	\$37.8	0.6%
Other	\$121.7	2.0%
<b>Total direct</b>	<b>\$5,959.7</b>	<b>100.0%</b>

Source: Access Economics projections.

It is always difficult to predict technological change, and it should also be noted that any increase in pharmaceutical spending, as new therapies become available, could be expected to have an offsetting effect on other medical costs, and also on indirect costs. Also important in projections is the policy response to the current inadequacies of residential and community care, carer programs, early intervention and research programs. If spending on these components is addressed in a significant way, there may be compositional and other effects on projected direct and indirect costs. We now turn to current estimates of the home and community care costs of dementia.

**2.1.3 Home and community care costs**

Home and community care costs (not included in direct costs for reasons given in the Methodology section) are derived from the proportion of the HACC program that is estimated to be spent on care for people with dementia – 20% of current Federal spending (\$674 million) or \$135 million<sup>75</sup> – plus spending on other dementia-specific programs (such as funding for Alzheimer’s Australia) which is estimated as \$40m in 2002.<sup>76</sup> The total, \$175 million, represents \$2,071 per person at home with dementia (52% of the total prevalence, or 84,394 people). Taking account of those who may not access the services (about 19%), the average cost is \$2,554 per person p.a. for those receiving them. This amounts to 16% of Department of Health and Ageing (DHA) spending on home and community care.

<sup>75</sup> The total HACC program, including State and Territory spending, amounts to \$1.1 billion.

<sup>76</sup> Unpublished DHA estimate.

Home and community care provision is significantly less costly to the public purse than residential care, as expected, which from Section 2.1.1 amounted to \$2,847 million or \$36,547 per person in residential care in 2002. This is, as expected, above the DHA published estimate of \$28,796 per person for all people in residential care, with or without dementia. The spending represents around 66% of aged care spending on residential care, \$4.3 billion in 2002-03. A summary is provided in Table 12 below.

**Table 12: Dementia Formal Care Costs, 2002**

	<b>\$m</b>	<b>per person at home</b>	<b>per person receiving services</b>	<b>% of total DHA</b>
<b>Home-based Aged Care</b>	\$175	\$2,071	\$2,554	16%
	<b>\$m</b>	<b>per person in place</b>	<b>DHA av. cost per occupied place</b>	<b>% of total DHA</b>
<b>Residential Aged Care</b>	\$2,847	\$36,547	\$28,796	66%
	<b>\$m</b>	<b>per person with dementia</b>	<b>per person receiving services</b>	<b>% of total DHA</b>
<b>Total</b>	\$3,022	\$18,620	\$19,773	56%

Source: Access Economics

## 2.2 INDIRECT FINANCIAL COSTS

### 2.2.1 Lower workforce participation of people with dementia

People over 65 with dementia have lower rates of employment than healthy people of the same age (as noted in Section 1.4.3), due to functional and cognitive disabilities. Table 7 showed that the employment rate for those with dementia is 2.3% compared to 8.5% in the general population. If older people with dementia achieved the same employment rate, there would have been an extra 9,612 people in the workforce in 2002, earning an average of \$696 per week, all other things being unchanged (see Methodology). This would have produced \$348.8m in extra income.

This figure may be a conservative estimate of the true loss as many people (particularly those under 65 who have not been included here) may reduce their workload rather than stop work completely, as a result of the health impacts of dementia. Income losses of families of people with dementia who reduce or give up work in order to care for the person with the illness are identified in the next section.

*"Mavis and I looked forward to the day I would retire. We had so many travel plans. We wanted to do so much when that time came. Unfortunately, retirement came too early and was unplanned. All our dreams have receded and we now deal with the reality of Alzheimer's."*

'Phillip'

*Margaret and Bill Carmen had been married for 19 years. At only 43, Margaret suddenly began to show signs of dementia and was diagnosed with Alzheimer's disease. A high school biology teacher, she had to give up work. Later her husband gave up his job to care for her full time.*

Hampson (2000), p18.

**Absenteeism:** There were an estimated 3,606 people employed, over age 65, with dementia in 2002, earning an estimated \$130.8m. Although data on absenteeism rates for Australian people with dementia who work are not available due to small sample size, a conservative estimate is likely to be around 5%

of work time lost (based on 8% lost for people with psychotic illnesses with similar cognitive and functional impairments). The cost of absenteeism would thus be a further \$6.5m.

*In total then, the loss of earnings from loss of employment and absenteeism is estimated for 2002 as \$355.3m.*

**Potential tax revenue foregone:** There are two sources of lost tax revenue that result from the lower earnings above—the potential income tax foregone and the potential indirect (sales) tax foregone. The latter is lost because, as income falls, so does consumption of goods and services. Table 13 summarises the tax losses of \$100m in 2002, comprising \$77m of personal income tax and \$23m of indirect tax.

**Table 13: Potential earnings and tax revenue lost due to dementia, 2002**

<b>Potential Earnings Lost</b>	<b>\$355.3 million</b>
Average personal income tax rate#	21.67%
Potential personal income tax lost	\$77.0 million
Average indirect tax rate#	12.5%
Potential indirect tax lost	\$22.8 million
<b>Total potential tax revenue lost</b>	<b>\$99.7 million</b>

# Source: AEM Model, Access Economics.

**Mortality burden:** In addition to the income foregone due to those with dementia in the community who are unable to work due to their illness, there is also the income foregone of those who have died prematurely due to dementia. Deaths from dementia in 2002 are estimated as in Table 14. These are likely to be significantly under-estimated (see Methodology) so the cost estimate of the mortality burden is very conservative. Assuming that if those who died prior to retirement age had lived and not had dementia, they would have been employed at the same rate as the general population over 65 – 8.5% (39 people in all would have been employed who were not because they died from dementia). The average age of death for those people aged 15-74 is 64.2 years (i.e., with 5.8 years to ‘average’ retirement) and the income stream is discounted at the average real growth rate in AWE (0.8% p.a.).

**Table 14: Deaths from dementia, Australia, by age and gender, 2002**

	<b>Males</b>	<b>Females</b>	<b>Persons</b>
0-14	12	7	18
15-34	1	4	5
35-54	3	5	8
55-74	234	216	450
75+	1,466	3,179	4,645
<b>Total deaths</b>	<b>1,716</b>	<b>3,411</b>	<b>5,127</b>

Source: Access Economics, based on Annex Table E from Mathers, Vos and Stevenson (1999).

This yields the net present value (NPV) of the mortality burden as \$8.8 million. The NPV of taxation revenue sacrificed for the mortality burden is \$2.5 million.

### **2.2.2 Family and carer costs**

As we have seen in Section 1.2, most people with dementia receive care at home initially, with day-to-day personal needs and support left very much to family and friends. Society, and our public sector health and welfare budget, relies increasingly on the support that such families and carers provide.

The approach adopted here is one of replacement cost (see Methodology), where the value of the hours of care is imputed as if a paid care worker provided them. Three tiers of care are modelled, based on the University of Michigan average hours of care for people with mild, moderate and severe dementia (see Section 1.5.1). The imputed carer rate is \$19.25 per hour, based on the Community and Aged Care Services (ACT) Award, 2002 (AW817098) for a Care Worker Grade 3, with adjustment for leave loading and after hours. Most of those with mild dementia (23% of total prevalence), about half of those with moderate dementia (22% of the total), and one quarter of those with severe dementia (7.5% of the total) are assumed to live at home, noting that many are in nursing homes for reasons other than dementia. The results are in Table 15, with the total value of families and carers for people with dementia estimated as \$1.71 billion in 2002. Associated tax foregone equates to \$489.7m.

The value of informal care of people with dementia was over \$1.7 billion in 2002.

*“I have been looking after Marjorie for 16 years but she has only required more personal care with things like eating, showering and toileting for the past five or six years. Until two years ago I used to spend three days a week in the office, but this is now one day only. Everyone said that I should retain an interest in my work as it would be a respite for me, and I certainly agree with that.”*

‘James’

**Table 15: Value of families and carers of people with dementia, 2002**

	No. of people with dementia at home	Hours per week of care required	Million hours of care	Value of care \$m
Mild	36,517	8.5	16.2	311.3
Moderate	35,705	25.0	46.5	895.3
Severe	12,172	41.5	26.3	506.6
<b>Total</b>	<b>84,394</b>		<b>89.0</b>	<b>1,713.2</b>

Source: Access Economics estimates.

Part of the value of informal care is compensated through Federal Government Programs, notably Carer Allowance (\$42.65 weekly in September 2002) and means-tested Carer Payment (\$214.70 weekly for singles). The means test (income and assets) is modelled to exclude the top 30%, and there is an allowance of 25% “wastage” (people who do not claim the payment for a variety of reasons). The value of the ‘transfer payments’, designed so that the burden of informal care is not borne wholly by the families and carers themselves, is thus estimated in Table 16 below as \$324m or 19% of the total burden.

Family carers provide 80% of the value of informal care without compensation.

**Table 16: Value of Carer Payment and Carer Allowance for people with dementia, 2002**

	Value of transfer payment	No. of people with dementia at home		Value of payments, \$m
		Before means test	After means test and wastage ie, receiving payment	
Mild	\$2,222	36,517	19,209	42.7
Moderate	\$11,186	35,705	18,782	210.1
Severe	\$11,186	12,172	6,403	71.6
<b>Total</b>		<b>84,394</b>	<b>44,394</b>	<b>324.4</b>

Source: Access Economics estimates.



### **2.2.3 Cost of welfare payments**

Many people living with dementia are reliant on welfare benefits as their main source of income. However, in most cases, this is the means-tested Age Pension, paid to eligible men over 65 and eligible women aged over 60-65, depending on their birth date (by 2014 the age will be 65 for everyone). Since the Age Pension would be paid to eligible elderly regardless of dementia, it is not included in modelling here.

People under retirement age with dementia may be eligible for the Disability Support Pension (DSP) and in some cases, Sickness Allowance. The DSP is the main means of income support in Australia for people aged 16 years and over whose physical, intellectual or psychiatric impairment prevents them from working, or for people who are permanently blind. There were some cutbacks to the program in the May 2002 Budget. Sickness Allowance provides assistance for people who are employed and who are temporarily unable to work (or study) due to a medical condition. It is not significant in the case of dementia so is not modelled here.

There are also entitlements to concession cards – Pensioner Concession Card (PCC) & Health Care Card (HCC), which may result in concessional transfers such as prescription medicines, transport fares, rates, power bills and car registration – and to Rent Assistance, for people who get a payment such as the Carer Payment and pay rent for private accommodation.

Although insufficient data precludes a firm estimate of many of these transfer payments (and they are likely to be relatively small as a proportion of the real total indirect costs anyway), a conservative estimate of welfare payments which includes the main items – DSP, Rent Assistance and Pharmaceutical Allowance – is provided in Table 17 below, totalling \$52.0m of which \$47.7m is DSP.

**Table 17: Cost of welfare payments**

	<b>weekly payment</b>	<b>receiving benefit</b>	<b>total cost \$m</b>
DSP (weighted)	\$ 196.95	4,653	47.7
Rent Allowance (weighted)	\$ 48.83	1,396	3.6
Pharmaceutical Allowance	\$ 2.90	4,653	0.7
<i>Total</i>			<i>52.0</i>

Source: Access Economics estimates utilising Centrelink rates of 20-Sept 2002.

### **2.2.4 Modifications and aids**

People with dementia and their families and carers may require a variety of additional equipment, aids and home modifications in order to continue living at home safely. These include memory aids (such as large-face clocks, signs and identifiers), bathing and toileting aids (eg, shower accessories, incontinence pads), safety aids (such as gas detectors, wandering/occupancy alarms), adapted cutlery and common items (eg, clothing with Velcro), daily pill boxes, mobility/transport aids (eg, walking frames, special shoes for “walkers”), nursing aids (eg, pressure-relief mattresses), grab rails, and so on.

There are a number of public programs for older people, people with a disability and their families and carers to assist them to make home modifications and provide aids and equipment that will help them to remain living in their own home avoid having to go into a residential care facility. The *Home Maintenance and Modification Program* is funded by the Commonwealth and State Governments under the HACC program, with two levels of assistance. The lower level of assistance is the Home Modification and Maintenance Services program, which includes installation of rails, provision of secure

rugs, hand showers, grab rails, moveable ramps and taps, as well as with minor home maintenance and repairs. Assistance with major work over \$5,000 is through the Home Maintenance Scheme, with the cost up to 20% of the total cost of the job.

The *Program of Appliances for Disabled People* (PADP) provides equipment and appliances to disabled people and some others, who are financially disadvantaged, including adjustable beds, hoists and mechanical lifters, shower chairs and bath seats. Access to continence aids – such as pads, uridomes, kylie sheets, commode chairs and toilet seats – is variable by State/Territory, with a summary of national, State and Territory programs provided in Continenence Foundation of Australia (2000).

The *Independent Living Centre* is a non-profit organisation that provides information about equipment, building design and other resources, as well as a display centre for people to view and sample a wide range of products and equipment, including aids for communication, lifting and transfers, continence, leisure and recreation, mobility, seating and transport.

Whether paid for privately or publicly, all these items incur additional indirect financial costs. Frisch (2001, Table 1, p18) undertook detailed survey work of the costs of aids, equipment and modifications in Australia, as shown in Table 18, averaging \$738.40 per person. Across all those people with dementia, the total cost in 2002 was \$119.8m.

**Table 18: Costs of aids, equipment and modifications, 2002**

	Mean cost pa per person (\$)	Annual cost all dementia (\$m)
Housing modifications	\$265.20	\$43.0
Aids and appliances	\$174.20	\$28.3
Consumables	\$299.00	\$48.5
<i>Total</i>	\$738.40	\$119.8

Source: Access Economics based on Physical Disability Council of DC Australia (Frisch, 2001) data.

### 2.2.5 Summary of financial costs

Table 19 and Chart 12 show the real indirect financial costs of dementia as \$2.2 billion, around two thirds of the direct health and ageing costs. Total real financial costs (direct and indirect) were \$5.6 billion. Interestingly, this is roughly equivalent to total Federal Government outlays for aged care services administered by the Department of Health and Ageing, estimated to be \$5.5 billion for 2002-2003 (about 0.77% of GDP).<sup>77</sup>

The total financial cost of dementia in 2002 was \$6.6 billion – over \$40,000pa per person with dementia

In addition, there were \$968 million of transfer payments – both lost revenue (tax foregone for people with dementia and their families and carers) and expenditure (welfare and carer payments). In total, indirect costs were \$3.17 billion (roughly equivalent to direct health and ageing costs). The total financial costs of dementia (direct and indirect, including additional net transfer payments) were \$6.58 billion in 2002.

By 2051, dementia's financial impact will total 3.3% of GDP

<sup>77</sup> As quoted in DHA (2002a) Attachment C.

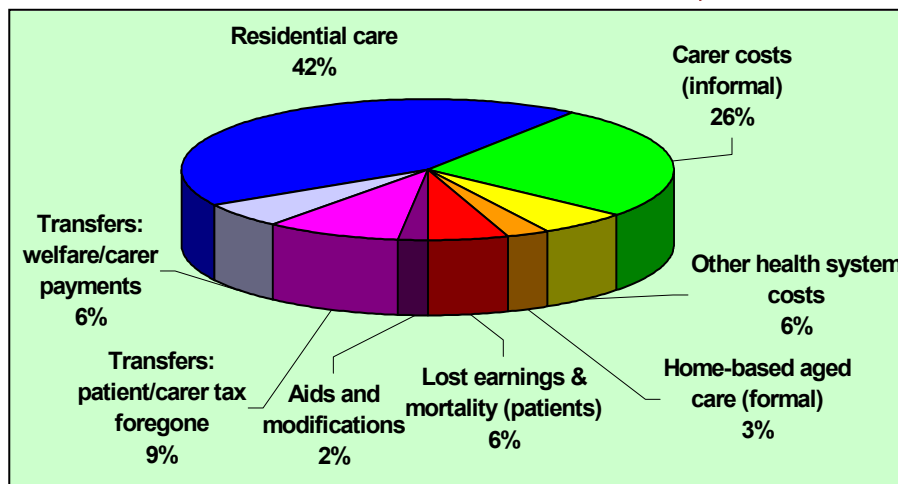
In per capita terms, the indirect financial costs of ageing are approaching \$20,000 per person with dementia p.a., while the direct health and ageing costs of dementia are over \$20,000 per person p.a., including home and community care of just over \$1,000 per person with dementia in 2002 (but \$2,554 per person receiving the care). Relative to national income, total financial costs are already approaching 1% of GDP and are set to reach 3.3% of GDP by mid-century<sup>78</sup>. Direct costs alone will reach 1.6% of GDP.

**Table 19: Summary of direct and indirect financial costs of dementia, 2002**

\$ million			Per person with dementia	% GDP 2002	%GDP 2051
	Real cost	Transfer payments			
<i>Direct health costs</i>	\$3,235.9		\$19,938	0.45%	1.6%
Including residential care	\$2,847.1		\$17,542*		
Home and community care	\$174.8		\$1,077*		
<i>Indirect financial costs</i>					
Lost earnings (patients)	\$355.3		\$355.3		
Mortality burden	\$8.8		\$8.8		
Tax foregone (patients)		\$102.2	\$102.2		
Value of carers	\$1,713.2	\$324.4	\$2,037.6	\$12,555	0.28%
Tax foregone (carers)		\$489.7	\$489.7		
Welfare payments		\$52.0	\$52.0		
Aids & modifications	\$119.8		\$119.8		
<i>Subtotal indirect financial costs</i>	\$2,197.2	\$968.3	\$3,165.4	\$19,504	0.44%
<b>Total financial costs</b>	<b>\$5,607.9</b>	<b>\$968.3</b>	<b>\$6,576.1</b>	<b>\$40,519</b>	<b>0.91%</b>

\*The averages per person with dementia in residential care and per person with dementia at home receiving formal services are \$36,547 and \$2,554 respectively (see Table 12). Source: Access Economics.

**Chart 12: Distribution of the financial costs of dementia, 2002**



Source: Access Economics.

### 2.3 THE BURDEN OF DISEASE

In 2002, over 5,000 Australians died from dementia (Table 14 Section 2.2.1), while thousands of others suffered from its disabling and distressing symptoms and its pervasive impacts on loved ones. Dementia

<sup>78</sup> Assuming ultra-conservatively only demographic growth and no increase in the real cost of care per person.

imposes burdens on people and their families and carers that go well beyond the financial costs. There is no objective way to ascertain a financial value for the pain, suffering and premature death from illnesses like dementia for all those involved. However, the internationally developed ‘Burden of Disease’ methodology (see Methodology) has earned recognition in Australia and overseas as a useful way of estimating the years of healthy life lost due to a condition. This method uses DALYs—or ‘disability adjusted life years’—as the measuring stick. DALYs have two components:

- the years of life lost (YLL) due to premature death—the mortality burden; and
- the years of healthy life lost due to disability (YLD)—the morbidity burden.

DALYs, YLLs and YLDs provide indicators that are useful in measuring the impact of disease and exploring the effectiveness of health spending in terms of purchasing years of healthy life. The Australian Institute of Health and Welfare has provided some excellent analysis in this area. Mathers, Vos and Stevenson (1999) estimate the burden of disease in 1996 for a variety of disease and injury categories. Table 20 extrapolates their estimates for dementia to 2002 using prevalence and demographic data.

Dementia cost over  
117,000 years of  
healthy life for  
Australians in 2002.

**Table 20: Burden of disease from dementia, 2002**

	<b>DALYs</b>	<b>YLL</b>	<b>YLD</b>
<b>Males</b>	<b>44,039</b>	<b>10,812</b>	<b>33,227</b>
0-14	358	358	-
15-34	36	36	-
35-54	1,388	50	1,338
55-74	17,704	2,542	15,163
75+	24,554	7,827	16,727
<b>Females</b>	<b>73,043</b>	<b>20,620</b>	<b>52,424</b>
0-14	204	204	-
15-34	112	112	-
35-54	1,578	118	1,461
55-74	22,858	2,778	20,081
75+	48,292	17,409	30,883
<b>Total</b>	<b>117,083</b>	<b>31,432</b>	<b>85,651</b>
0-14	562	562	-
15-34	147	147	-
35-54	2,966	168	2,799
55-74	40,561	5,320	35,244
75+	72,846	25,236	47,610

Source: Access Economics, utilising data from Mathers, Vos and Stevenson (1999).

In Australia in 2002, the burden of disease attributable to dementia was estimated as 117,083 DALYs. Morbidity was the major source of burden (85,651 YLDs were 73% of the total) while mortality accounted for 31,432 YLLs or 27%. Females bore 62% of the overall burden of disease and the same proportion was borne by people aged over 75. It is noteworthy that the disability weights for dementia are 0.27 for mild cases, 0.63 for moderate cases, and 0.94 for severe dementia. The latter is the highest disability weight for all illnesses, equal with severe rheumatoid arthritis and higher than that of final stage terminal cancer (0.93). This shows the extent of the disability burden for dementia compared with other illnesses. The next section provides further comparison with other diseases.

### 3. COMPARISONS, CONSTRAINTS AND SCENARIOS

#### 3.1 COMPARISONS WITH OTHER DISEASES

Dementia is one of the leading causes of health system costs and disease burden in Australia. National Health Priority areas, which account for over 70% of the total burden of disease (DALYs), are currently:

- Cardiovascular disease
- Cancers
- Mental health
- Injury
- Diabetes
- Asthma
- Arthritis and musculoskeletal disease

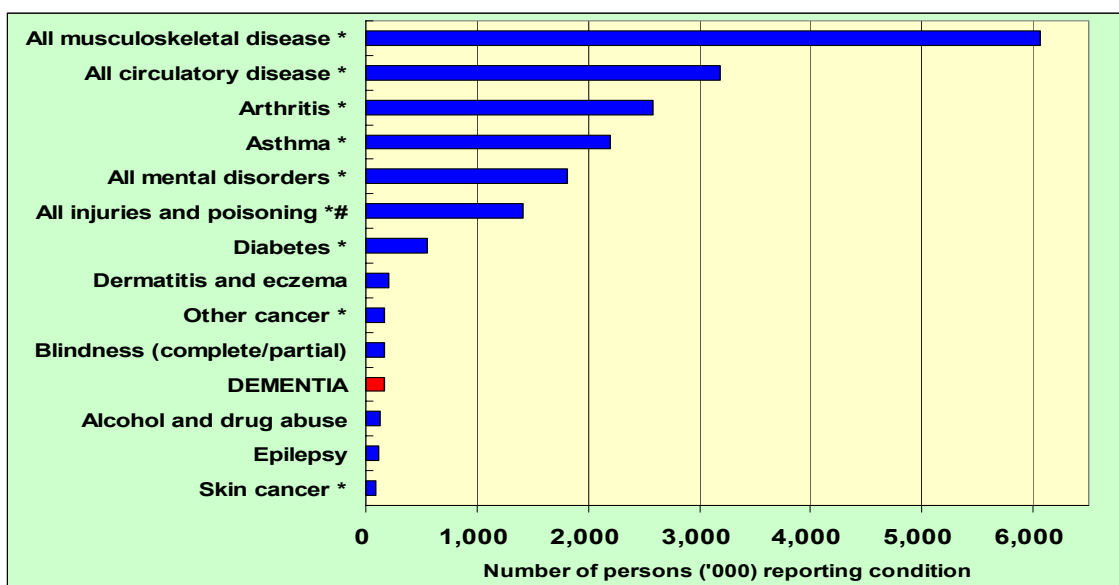
Dementia is more common than epilepsy or skin cancer.

While dementia falls within the Mental Health priority area, the main policy focus within mental health so far has been on depression. This section compares the prevalence, health costs and disease burden of dementia with other illnesses, including the National Health Priority areas.

##### 3.1.1 Comparisons of prevalence

Chart 13 compares the prevalence of selected disorders in Australia according to the latest data from the National Health Survey, released in October 2002 and relating to the year 2001. National health priority areas are asterisked. Musculoskeletal disease, of which arthritis is the largest component, dominates the profile, followed by circulatory disease. Asthma is also very common, affecting over 2m Australians, while 1.8m have mental disorders and around 1.4m suffer injuries (including poisoning). Diabetes affects over half a million Australians. The prevalence of dementia is of the same order of magnitude as partial and complete blindness, and cancers (excluding skin cancer, the most common form) and slightly less than dermatitis and eczema combined. Dementia is more common than epilepsy or skin cancer, and the NHS data also indicate higher prevalence than alcohol and drug abuse. Dementia is more common than any other neuro-degenerative condition, including Multiple Sclerosis.

**Chart 13: Prevalence of selected conditions, 2001**



Source: Access Economics based on ABS (2002) 2001 National Health Survey data. # estimated from ABS (1997) 1995 NHS data. \* = National health priority areas.



### 3.1.2 Comparison of financial costs

Table 21 compares the direct health system costs of dementia with those of other disorders, including the national health priority areas, according to Mathers and Penm (1999)<sup>79</sup>. Circulatory disease was the most costly, as a result of its impact on the hospital system. Digestive diseases (largely dental problems, ulcers and hernias) are second highest because of their dental costs. Musculoskeletal disease is third, due mainly to the various impacts of arthritis and osteoporosis across the health system. Injuries (including self-inflicted injury) also have high hospital costs, just tipping them above mental illnesses in the year of comparison. Mental illness is next, representing over 8% of total health costs. Dementia is the most costly component of mental health, as noted in Table 9 (Section 2.1.1). Of all expenditure on health, dementia was already 2.3% by 1993-94, 20% of nursing home costs. As noted in Section 2.1.1, the nursing home costs of dementia were likely underestimated by half in 1993-94, putting the probable contribution of dementia closer to \$1.4 to \$1.5 billion.

**Table 21: Comparison of direct costs, 1993-94**

Disease category (ICD-9 chapter)	Total Costs	Hospitals	Medical	Pharma- ceuticals	Dental & allied health	Nursing homes	Other
Circulatory*	3,719	1,657	503	715	40	587	218
Digestive	3,715	1,070	284	275	1,849	35	202
Musculoskeletal*	3,002	1,207	518	276	416	430	154
Injury*	2,601	1,663	393	127	160	112	146
<b>Mental*</b>	<b>2,586</b>	<b>1,007</b>	<b>432</b>	<b>198</b>	<b>83</b>	<b>718</b>	<b>147</b>
<b>of which dementia</b>	<b>714</b>	<b>110</b>	<b>11</b>	<b>2</b>	<b>4</b>	<b>539</b>	<b>48</b>
Respiratory (inc. asthma*)	2,521	833	624	784	37	107	135
Nervous system	2,334	766	431	248	227	503	159
Cancer*	1,904	1,327	261	53	12	32	219
Genito-urinary	1,662	997	383	143	17	32	90
Symptoms	1,334	478	426	302	57	5	66
Complications of pregnancy	1,051	941	32	11	6	-	60
Endocrine (inc. diabetes*)	966	235	222	309	54	47	98
Skin	956	336	247	259	56	6	53
Infectious	849	246	316	193	15	13	65
Other	2,197	1,297	566	148	45	21	117
<b>Total</b>	<b>31,397</b>	<b>14,062</b>	<b>5,640</b>	<b>4,042</b>	<b>3,075</b>	<b>2,647</b>	<b>1,932</b>
<b>Dementia as % of total</b>	<b>2.3%</b>	<b>0.8%</b>	<b>0.2%</b>	<b>0.1%</b>	<b>0.1%</b>	<b>20.4%</b>	<b>2.5%</b>

Source: Mathers and Penm (1999), Table 1, p2 and special AIHW data request for dementia.

However, it is noteworthy that circulatory and digestive disorders, as well as cancer, injuries, diabetes and asthma, are likely to have smaller *indirect* costs since the requirement for ongoing carers is not so high. With cancer and circulatory disease, this is unfortunately because of their high fatality rate, while in the others it is because treatment and management enable lower levels of disability and care or, in the case of injuries, a higher rate of recovery. Because of the substantial carer costs for dementia, it is likely to rank extremely highly in indirect costs, although insufficient comparable data are available to draw sound conclusions. Musculoskeletal disease would probably rank highest due to both high prevalence and high disability burden.

At least \$1 in every \$40 in the Australian health system is spent on dementia.

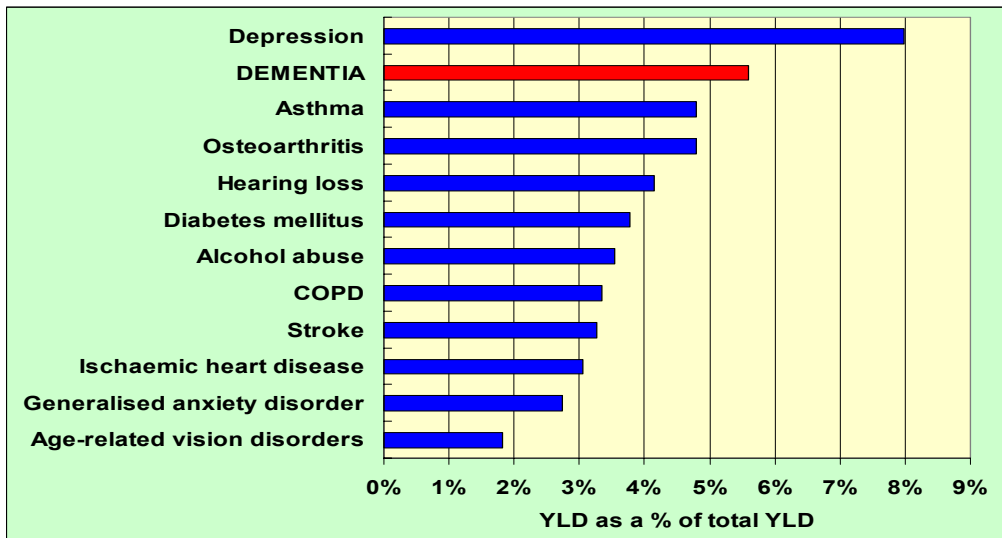
<sup>79</sup> Although this data relates to the year 1993-94, it is the most recent available. Updated cost data are expected from the AIHW in June 2003.

### 3.1.3 Comparison of disease burden

It is in terms of the burden of disease from disability that dementia is most costly. More years of life are lost due to disability (YLD) from dementia (5.6% of the total) than from every other national health priority area, second only to depression (8.0%), as shown in Chart 14. Asthma ranks third (4.8%), followed closely by osteoarthritis (also 4.8%), hearing loss (4.1%) and diabetes (3.8%). Cardiovascular disorders (such as stroke and ischaemic heart disease) also rank in the top ten. Dementia is the second highest disability burden for women and the fourth highest for men (Mathers, Vos and Stevenson, 1999, p51, T4.3).

The disability burden of dementia is higher than that of every other national health priority.

**Chart 14: Ten leading causes of years of life lost due to disability (YLD), 1996**



Source: Mathers, Vos and Stevenson (1999), Figure 2, pxxv.

In terms of total DALYs, including the YLL or mortality burden, dementia ranks fourth highest for women and tenth for men, of all disorders. For older Australians, these rankings rise to third (8.9% of the total disease burden) and fifth respectively (5.3%). Table 22 shows the contribution of dementia to the total burden of disease for older Australians. The only greater threats to older Australians are smoking-related – ischaemic heart disease, stroke, lung cancer and chronic obstructive pulmonary disease (the latter two for men only).

Dementia carries the greatest burden of disease for older Australians, unrelated to smoking.

**Table 22: Contribution to the total burden of disease for older Australians**

Males		% of DALYs	Females		% of DALYs
1	Ischaemic heart disease	21.7	1	Ischaemic heart disease	20.3
2	Stroke	8.6	2	Stroke	10.7
3	Lung cancer	6.9	3	<b>Dementia</b>	<b>8.9</b>
4	COPD	5.8	4	COPD	4.0
5	<b>Dementia</b>	<b>5.3</b>	5	Breast cancer	3.6
6	Prostate cancer	5.1	6	Colorectal cancer	3.4
7	Colorectal cancer	3.8	7	Lung cancer	3.1
8	Diabetes mellitus	3.0	8	Age-related vision disorders	2.8
9	Adult-onset hearing loss	2.9	9	Diabetes mellitus	2.8
10	Benign prostatic hypertrophy	1.9	10	Osteoarthritis	2.2

Source: Mathers, Vos and Stevenson (1999), Table 5.9 p73.

## 3.2 CONSTRAINTS TO SERVICE DELIVERY

This section identifies constraints to current service delivery and to extending service provision to meet projected need, including medical and hospital services, pharmaceuticals, research, residential care, home and community programs, and demand/distributional issues in the health financing system. A solution-focused approach is adopted, which is developed further in the following chapter on strategies.

### 3.2.1 *Medical and hospital services*

**Early detection:** As noted in previous sections, although GPs are often the first contact for people with dementia and their families and carers, they are often not equipped to carry out the more comprehensive psychometric screening nor have the skills to diagnose the early stages of dementia or complex and unusual dementias. Interventions are required to assist GPs (and others) in detecting dementia. Extension of specialist services for early detection of dementia, for example through memory clinics, is important.

The **General Practitioner Assessment of Cognition (GPCOG)**, a recent screening tool, has been recommended by Professor Henry Brodaty as valid, reliable, quick to administer (less than 4 minutes for most), easy to use and acceptable to GPs and their patients, representing an advance over former screening tests – performing as well as the Abbreviated Mental Test and at least as well as the MMSE. Many GPs require more information about how to administer the GPCOG and differential diagnosis of cognitive impairment, although MMSE should also continue to be encouraged.

Using PET scans in the early stage diagnostic process for AD has been found to reduce the false-positive rate by half and the false-negative rate by 60%. This new analysis, presented by University of California (Los Angeles) researcher Dr Silverman at the American Academy of Molecular Imaging in October 2002, suggested that patients could be kept out of nursing homes for 9 to 18 months longer through such early diagnosis and the use of early treatment of AD with cholinesterase inhibitors. He also found that early diagnosis and treatment could substantially reduce medical and hospital costs. Expanded use of PET scans may not be possible in Australia in the near future however.

**Supplementary education of GPs and primary care workers** is also required to assist them in caring for patients subsequent to screening. This should include dementia management principles with the goal of recognising highly trained GPs as '**dementia-accredited GPs**'. This is in keeping with the de-institutionalisation of mental health care over the past two decades, the burden of which has fallen largely to GPs. Increased remuneration is indicated for the higher skills levels required for such accreditation, perhaps in the style of current Enhanced Primary Care (EPC) Medicare items. There are also constraints to GPs attending patients in nursing homes, in part due to the remuneration structure. New information technology initiatives such as teleconferencing may provide support for GPs who are more isolated. Information technology may also be of use in GP education and referencing programs.

**Acute care hospitals:** Acute hospital costs could be reduced by reducing the time (four times the ALOS) that dementia patients are hospitalised awaiting transfer to a high care facility. Such transfers comprise nearly two thirds of entries to high care. Ongoing monitoring is required to assess potential mechanisms for reducing these wait times, and the cost-effectiveness, appropriateness and equity considerations of such interventions. Access to dementia-trained nursing staff should be available also in acute care hospitals for the period of the 'wait'. Acute care providers report that they need more training, resources (including geriatricians) and strategies to manage people with dementia (secure environments, appropriate assessment tools, care and discharge planning). These issues are being addressed in some States through "Innovative Places" and similar models.

### 3.2.2 Pharmaceuticals

Early access to medications at an affordable price is another constraint for people with dementia and their families and carers. Access is currently constrained by:

- an overly rigid definition of 'acceptable benefit' (which excludes *maintenance* of existing cognitive function in a *progressive* condition, and also excludes improved social functioning, which reduces carer burden and delays institutionalisation);
- the exclusion of people with non-AD forms of dementia; and
- administrative arrangements that can result in unintended and adverse outcomes.

Disadvantaged groups include people with non-Alzheimer dementia and all people with dementia who need anti-psychotic treatments.

Moreover, such cost-cutting measures – targeting pharmaceutical expenditures – have been found in numerous studies to be ineffective in reducing overall health costs. Rather, they have been found to increase overall health costs by 30-50%. Horn (2002) summarises current research, which has shown that:

- limiting doctors' prescribing choices was found to be associated with increased overall utilisation of pharmaceuticals;
- there are significant associations between formulary restrictions in a drug class and higher health care utilisation (GP or emergency department visits, additional prescriptions, hospitalisations);
- the negative effects of formulary restrictions lead to particularly suboptimal therapy and outcomes for older people;
- patients with pharmaceutical capitation had 14% higher total health costs than non-capitated patients and 29% higher pharmaceutical costs (although this is not currently important for the Australian system);
- newer drugs are often those targeted for cost-control because they can be most expensive; yet these can offer the best outcomes as they are likely to have fewer side effects, improved safety and efficacy, greater ease in use, increased compliance and be better tailored to individual needs;
- best practice drug use can result in lower carer absenteeism, lower employee turnover and greater labour productivity;
- if the only options are to control or not control drug access, then *not controlling* is the *better choice*.

PBS 'cost-cutting' measures could be increasing overall health care costs by 30-50%.

"Rising drug costs are, in general, part of the solution, not part of the problem."  
Kleinke (2001)

There is a third option, however – discovering, through clinical practice improvement (CPI) studies what the best treatments for specific types of patients are, and implementing them as guidelines. CPIs can uncover important, sometimes surprising and cost-saving results. Kleinke (2000) concludes that the best strategy for preventing over-use and inappropriate use of pharmaceuticals is to tie utilisation of drugs to best practice research and established clinical guidelines.

One example is the treatment of agitation in dementia. Cost-cutting regulation has aimed at discouraging the use of psychiatric medications in the treatment of dementia in nursing homes and the limitation of pharmacotherapy to monotherapy. However, CPI studies have shown that this intervention has in fact increased overall costs relative to combination therapy.

Another example studied limiting both access to psychiatric drugs and visits to mental health providers. This was associated with higher total health care costs. In contrast, unlimited and early access to best practice mental health care for another firm (Merrill Lynch) was shown to reduce costs per employee by 25%.

Dr Horn provides other examples for treatment of depression, asthma, arthritis, ulcers, hypertension and antibiotics. She concludes that drug costs are not a cost item to be managed, but a health maintenance item to be leveraged.

*“Curtailling access to medications via cost-control mechanisms can adversely affect other health costs and increase total health care utilisation”.*

Horn (2002)

### 3.2.3 Research

Section 2.1.1 on direct costs showed that, projecting official AIHW estimates of public research on dementia in 1993-94 of \$8.4m, Australia in 2002 spent around \$19.2 million on such research. This equates to \$118 per person with dementia per annum, or \$1 on research for each \$342 of the total costs of dementia (0.29%). However, Jorm et al (2001) and Maller and Rees (2002) note that this growth (the ‘normal’ for the sector) has not occurred for dementia and that in fact, official money spent on dementia research may be as little as \$2.5m in 2000<sup>80</sup> – less than 1% of all NHMRC research expenditure (\$15.40 per person with dementia and \$1 for every \$2,630 that dementia costs). Alzheimer’s Australia generates from trust funds a mere \$40,000 annually to extend towards research grants, compared with US\$120m (A\$240m) that the US Alzheimer’s Association has granted since 1982 – over 25 times the annual per capita level in Australia.<sup>81</sup>

Other international comparisons (summarised in Table 23), while not directly comparable, suggest that:

- Spending on AD research in the United States is A\$300 per person (A\$1.2billion in total), with calls from stakeholders to increase it to US\$1bn (A\$2bn or A\$500 per person).
- In the UK, research funding on AD is trivial – 60% of the amount spent on stroke, less than 10% of the amount spent on heart disease and only 3% of the amount spent on cancer (Lowin et al, 2000).
- In Canada, the 1991 data are similar to the AIHW data for Australia in 1993-94, around 0.25% of the cost of the disease.

**Table 23: Comparisons of costs and research allocations, Australia, Canada, US and UK**

Comparisons	Australia, AE 2002	Australia, Jorm, 2000	US, 1996-2002	UK, 2000	Canada (1991, conservative)
People with dementia	162,297	162,297	4,000,000	710,000	250,000
Total costs (\$Am)	\$6,576	\$6,576	\$200,000	\$31,576	\$3,894
Cost per person (\$A)	\$40,519	\$40,519	\$40-50,000	\$44,473	\$15,575
Research costs (\$Am)	\$19.2	\$2.5	\$1,198	\$23.5	\$10.9
Research (A\$/person)	\$118.36	\$15.40	\$300	\$33.15	\$43.61
Total costs: research costs	\$342	\$2,630	\$167	\$1,341	\$397

Source: Access Economics using exchange rates of A\$1=\$US0.50 = C\$0.8989 = UK£0.3484.

<sup>80</sup> A search on keywords ‘dementia’ and ‘Alzh’ showed \$5.36m in NHMRC grants for 2002 and \$42.4m for 1995-2002.

<sup>81</sup> A\$240m / 14 (population factor) / 20 (years) / 30,000 (\$A in Australia) = 28.6 times larger



In Australia, if we took the current US level as a comparator (\$300 per person), we should be spending \$49m per annum on officially funded dementia research; if we used the US *goal* as a comparator, we should be spending \$81m p.a. As middle ground, if we aimed to make research 1% of the total costs of dementia each year, we should be spending \$66m p.a.

Australia, as a 'knowledge nation', has comparative advantages in innovative research and development, and should be pulling our weight internationally in this critical area. Large pharmaceutical companies are already spending substantial resources on medications and vaccine research. However, there is a critical gap both in Australia and overseas for research into better clinical practice and care, in a country whose aged system is in many ways world class. Less than 10% of our research on dementia involves the investigation of services, and this knowledge is less importable because there is so much that is unique to the Australian situation (Jorm, 2001). In the area of dementia services, research should focus on:

- the key factors that make staying at home more or less likely - including understanding better the role of psychosocial approaches to keeping people with dementia at home;
- the importance of new technology in the design and modification of homes;
- the importance of autonomy in user satisfaction with long-term care and the role of the consumer as budget holder;
- the evidence available for achieving better co-ordination of services - in the community and at discharge from hospital in particular;
- the meaning of 'domestic' / 'homely' in the context of residential care;
- the advantages and disadvantages of early diagnosis for a consumer and the role of memory clinics;
- the profile of the minority who will need dementia specific care.

In sum, Australia has fallen behind substantially in dementia research. Greater investment in research is imperative in meeting the challenges presented by the dementia epidemic, with priority accorded to research on care practices and the delivery of services as well as bio-medical and medical research.

*"Given the magnitude of potential savings – including savings to public health care programs – if Alzheimer's disease could be prevented or arrested at an early age, a substantially increased federal commitment to Alzheimer's disease research is clearly warranted... There are few signs that public or private research is being undertaken at a scale warranted by the magnitude of the disease's costs."*

Hay and Ernst, quoted in Lowin, McCrone and Knapp (2000)

### **3.2.4 Home and community care**

Constraints arise in community care in two areas - in-home support services and support for families and carers. For **in-home support services**, the barriers are primarily financial. Many people cannot adequately access home-based maintenance and support through HACC and more intensive support, such as CACPs. Recent increased HACC budget allocations in FY2002-03, while welcome, have fallen short of addressing unmet need. Additional funding would ease these constraints. Steps also need to be taken to ensure that all HACC, CACP and EACH services are capable of supporting people living in the community with dementia. As with the residential sector, this will require additional training for staff, beyond its current respite worker focus, to ensure that all staff in services that have contact with older people are in a position to understand the needs of people with dementia and how those needs impact on service delivery. While staff training is normally an employer responsibility the structure of the community services sector makes it very difficult for organisations to meet the costs of additional

training. Accordingly Government support for the cost of this training should be provided. The existing CEWT program is a cost-effective model that could be expanded to meet this need.



In terms of **family and carer support**, the issues are not just financial – innovative models are required. The 2002-03 Federal Budget included an extra \$80 million to help families and carers over the next four years, with \$30 million to expand the number of respite services, assist with the cost of equipment and transport and provide emotional and psychological support for families and carers.<sup>82</sup> A further \$20 million is to help families and carers of people with dementia to obtain residential respite and increase access to specialist psychogeriatric advice and support. An

additional \$30 million will support ageing families and carers of people with disabilities by providing education and training for volunteer carers, targeted care packages and assistance with purchasing care services and equipment. A Commonwealth *Carer Resource Centre* in each capital city acts as a single contact point for carers seeking information and advice about the full range of services available to them. The Government is also funding the development and distribution of some carer resource materials.

While these measures provide a good basis there remain large gaps in the following three key areas.

### 1. Respite

Funding for the National Respite for Carers Program has increased from \$19 million in 1996-97 to an estimated \$88 million in 2002-03. This represents a good start, however, much existing respite care is not appropriate for carers of people with dementia, who require regular respite care that is responsive to key changes in their situation, with the capacity to also support them in emergencies. Respite care for younger people with dementia can be particularly inappropriate.

Respite is an essential part of dementia care. It must be tailored, timely, linked with other types of support and provided by knowledgeable, skilled and flexible helpers.

The quantity of residential respite care available is capped at 63 days maximum in a financial year (one day in six, with an additional 21 days in special circumstances). More in line with other work weeks would be two days in seven (including nights) – 104 days per FY – plus annual holidays. However, the existing places are in fact under-utilised (64% of available allocated respite days in residential facilities are used), with the 2002 Budget including funding to increase the take-up rate of residential respite. As a consequence the Commonwealth is utilising such funds increasingly through brokerage.

Funding for the Early Stage Dementia Support and Respite program (currently being evaluated) needs to be extended, or new funding provided for a new program for support and respite for people with mid-stage dementia. Additional funding for support is likely to be particularly cost-effective in reducing carer burden and delaying institutionalisation (see Section 3.3.2).

<sup>82</sup> Carers Australia (2001) identified transport and equipment costs as one of a number of priority areas for the 2002-03 Budget. Regarding emotional support for carers, Carers Australia seeks to develop ongoing partnerships for a range of counselling models (including personal and relationship counselling, family conferencing and telegroup counselling services) for carers and their families, including subsidising carers who are unable to meet the user charges for counselling services.

Moreover, more flexible *models of respite care* are needed, including overnight and weekend support, cottage style accommodation, extended hours at day centres and extension to many areas where there are access problems and service gaps.

## 2. Carer education

*“Most carers do not have access to appropriate education programs to assist them in their caring role... In a recent national health and wellbeing survey, 33% of respondents reported physical injuries as a result of providing care, but 49% of respondents had never received information or practical training.”*  
Carers Australia (2001)

There remains a lack of access for family carers to informal, practical, age-appropriate and culturally sensitive instruction and advice tailored to their immediate and continuing needs. This need must be met with the assistance of people with first hand experience of dementia care. Additional funding is required, ideally channelled through Carer's Associations and Alzheimer's Australia, to:

- subsidise respite care and other participation costs for family carers who need financial assistance to take advantage of the education program;
- expand national Alzheimer's Australia programs to enhance support groups, counselling, training and 'living with memory loss' programs;
- expand dementia specific and quality person-centred care programs to respite service providers and residential care staff.



***Above: Donald, 29, assists his grandmother, Mary, with all of her basic needs***

The pioneering work of the late Professor Tom Kitwood of the Bradford Dementia Group has contributed significantly to quality of care outcomes for dementia care, including carer training programs based on his person-centred principles (Kitwood, 1997). The University of Bradford (2001) has instigated the first UK undergraduate degree in Dementia Studies based on his work, including distance learning and key techniques such as *Dementia Care Mapping*, devised by Kitwood as a way of consulting with people with dementia who may not find it easy to comment through questionnaires or focus groups.

**Dementia Care Mapping** is a method of evaluating and improving the care given to people with dementia in home-based, respite and institutional settings. 'Mappers' make detailed observations of people with dementia in a particular setting, recording what they see on a grid. Observations are carried out over a prolonged period of 6 - 8 hours covering the full waking day of residents. The resulting data offers a 'map' which shows in summary how each resident fared - what they did throughout the day, what they enjoyed and what caused them distress. It shows how care is distributed among the group, notable characteristics of the style of care as well as an overall index of the general quality of the service. It can highlight individual needs of residents that have perhaps gone unrecognised as well as 'high spots' in a person's day that indicate particularly good practice. Ongoing training with staff on site by the Dementia Team can enhance the good practice and help make necessary improvements.

### **3. Workforce opportunities to assist families and carers in being able to maximise employment**

Currently there are few initiatives that target employers of family carers. The goal would be to enable them to develop strategies for more flexible work practices in order to retain participation rates of trained workers. As the demographic transition continues, participation rates – particularly of women – will become increasingly important in maintaining economic growth as well as sustainable public sector revenues from taxation. These factors were noted in the Federal Government's InterGenerational Report, launched with the May 2002 Budget.

Possibilities might include part-time home-based work, work-based adult day-centres, or access to work-based services for family carers such as counselling or exercise programs. In addition, dementia awareness and destigmatisation courses could be introduced in workplaces. A few pilot trials of such initiatives should be implemented, based on international pilots.

#### **3.2.5 Residential care**

After an ACAT has made a recommendation for transition of a person with dementia to appropriate residential care, it will often provide a list of local facilities, although in many areas in Australia the 'good ones' are likely to have waiting lists exceeding a year. Even if a place becomes available, it may not suit the individual (eg, same gender preferences for shared rooms in some low-care facilities). Moreover, the accommodation provider may be seeking a person without challenging behaviours, yet the reason for seeking care may have been that the family carer is unable to cope with a demanding phase of BPSD. Often decisions are made under pressure, and the family carer takes whatever becomes available, which can result in deep dissatisfaction, particularly if promised services (such as specific therapies) are not forthcoming or if the quality of care is not up to expectations.

Nursing and personal care staff are not well remunerated. There has been exposure in recent years of a number of cases where residents have been inappropriately drugged, restrained or neglected. Rosewarne et al (2000) found that half of all high care facilities reported regular use of 'chemical' restraint and one third reported regular use of 'physical' restraint. Across all facilities, chemical and physical restraint were used rarely or never in 48% of facilities, sometimes in 36%, and often or regularly in 16%. Facilities that had a 'no restraint' policy found that if restraint was not an option, staff tried much harder to find other more appropriate solutions. The Australian government has recently funded a national project to provide education and training materials for aged care staff regarding the appropriate use of restraints.

#### **Existing dementia-specific care**

With the number of high care beds strictly controlled since ACATs were established, although waiting lists<sup>83</sup> for nursing homes are reduced, the impairment of those admitted and consequent nursing requirements have increased. Although a large and growing proportion of high care residents have dementia, the design, staffing and management of nursing home services have been geared more to physical disabilities with limited scope to manage the particular BPSD needs of dementia residents.<sup>84</sup> This has led to greater demand for dementia-specific care facilities, although policy remains to

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<sup>83</sup> Entry period (the days between ACAT assessment and entry into residential care) has increased however, and is a poor proxy for waiting time. For more detail, see AIHW (2002c).

<sup>84</sup> One example is the ability to manage late afternoon restlessness common among people with dementia, often termed 'sundowning'. The reason for this behaviour is thought to be past history of busy-ness with children and meals, and many dementia residents still feel an unclear call to action, leading to agitation and often wandering. Specific therapies and skills are required to caringly manage these behaviours, as well as fairly high staff-to-resident ratios.

accommodate mobile people with dementia in low care facilities, reflected in the allocation of a large proportion of the low care places in recent Aged Care Approval Rounds to people with dementia, even though their ACAT assessment may be 'high care'. ACAT assessments do not reflect the optimal type of *environment* for the person, and therefore the type of accommodation payment that is most appropriate.

For low care facilities, 85% of residents with dementia are supported in mainstream areas (15% in dementia-specific areas); for high care facilities, the comparable figure is 92% (and 8%). Hostels have, since the termination of Dementia Grants<sup>85</sup>, struck funding problems, mainly because recurrent costs are higher due to the special requirements of dementia care, yet residents must be assessed as 'low-care' (which often they are not) in order to gain a place. Conversely, there are disincentives to invest in high care facilities because it is so difficult for providers to cover the capital costs (without accommodation bonds), and this may not be appropriate for mobile people anyway who need personal rather than nursing care. There is the option of becoming an ESP, although these places are too limited to be able to adequately cross-subsidise, which in any case is sub-optimal and potentially inequitable.

More dementia-specific places are needed, particularly for those who are ambulant and have challenging behaviours.

As noted earlier (Section 1.2.9), over 90% of people in high care and 54% of people in low care facilities have dementia or cognitive impairment, yet only 6% of residential care beds are dementia-specific. The capacity for residential care to support people with dementia (both facilities and workforce training) is a serious constraint. There are too few places specifically designed to support people with dementia with challenging behaviours or other special needs, and inadequate training for staff caring for these people. It is estimated that at any time 10% of residents with dementia will require special support.

Recurrent costs constrain 'low care' dementia places. Capital costs constrain 'high care' dementia places, even when these are appropriate.

A final issue is care for people with severe (physically aggressive or violent) BPSD. These 1% of people with dementia who need mental health and aged care services may be unable to access either state mental health or Commonwealth funded aged care. This represents a significant gap in the care system.

*Finding care for the person with dementia can be extremely challenging. It is widely acknowledged that there is a nationwide shortage of dementia-specific residential accommodation. Such homes require a higher staff-to-resident ratio and a higher level of security, and they need to offer appropriate therapies and facilities, such as safe walking areas for residents. Ideally they are smaller, with only 10-15 residents – a comfortable number of new faces for the person with dementia to deal with.*

Hampson (2000), p227.

### Summary of issues for existing residential facilities

- increased ongoing training for all care staff in dementia-specific and quality person-centred care principles;
- staff-to-resident ratios that address understaffing, with guidelines on the appropriate mix of nursing and personal care staff;
- tighter accreditation and monitoring of standards to actively ensure quality care, with restrictions placed on chemical and physical restraint practices;

<sup>85</sup> Dementia Grants Program funding was made available to all low care facilities for a period of eight years from the mid-1980s.



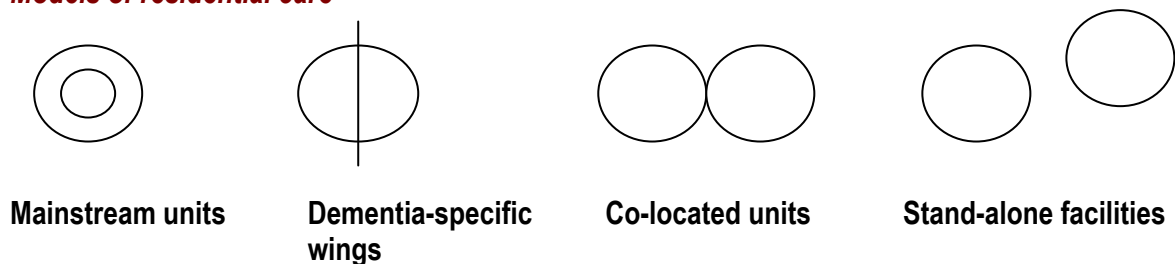
- review of remuneration for nursing and personal care staff;
- planning ratios need to make provision for dementia care and challenging BPSD;
- descriptors in the RCS should concord with ACAT assessments; ‘high care’ should include the need for behaviour management and environment, not just the need for nursing care;
- potential perverse incentives in the RCS relating to behaviour need to be addressed with increased rating/funding also attached to interventions which will *prevent* challenging behaviours rather than rating/funding solely favouring *managing* challenging behaviours;
- overall numbers of places and sustainable funding mechanisms (see Section 3.2.6 below); and
- greater access to care for people with severely aggressive behaviours.

**New models of residential care**

Suppose we were starting from scratch and knew what we know today. To promote ageing-in-place, we would want to have integrated facilities that could cater for a range of different needs as a person ages, rather than having to move them to a new location. We would want to be able to cater for the specific needs of the large proportion of residents who have dementia or cognitive impairment, or could develop these in later years. We would want to have staff who were trained in dementia-specific and quality aged care principles, as well as facilities that were appropriate for the various stages of ageing as well as the mild, moderate and severe stages of dementia – including secure walking areas, a few segregated areas for people with highly challenging behaviours, low care areas for mobile people and high care nursing areas for those less mobile.

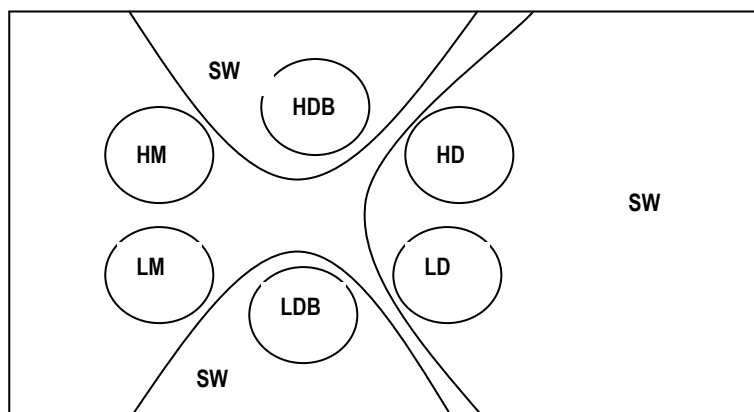
Rosewarne et al (2000) proposes the ‘**Cluster house campus model**’ – separate buildings (‘houses’) each with around 15 beds within a single complex (‘campus’) of around 90 beds. The houses would operate largely as independent care units with a caregiver supported by an on-staff visiting registered nurse. “The campus could have houses for the more behaviourally disturbed, for those with high physical care needs and for those who require secure wandering areas... The care follows the resident, ie, residents do not have to be moved to an entirely new location as they become more dependent. The necessity for developing specialised stand-alone dementia facilities is becoming less critical as this mixed campus approach becomes more widely adopted” (p51). The diagram below illustrates current models of care facilities, compared with a cluster house campus.

**Models of residential care**



H high nursing care  
 L low nursing care  
 M ‘mainstream’ residents  
 D residents with dementia  
 SW secure walking areas  
 B residents with BPSD

**Cluster Housing**



For care assessment and placement purposes, behaviours might be stratified as B1, B2, B3 and B4, based on Rosewarne et al (2000) descriptors, with:

B1: problem behaviours requiring basic management and occasional intervention;

B2: episodic problem behaviours requiring frequent intervention and expert management;

B3: continuously disruptive problem behaviours requiring frequent intervention and expert management;

B4: continuously disruptive problem behaviours requiring management in specialist psychiatric facilities.

There is also broad concordance with the seven tiers of descriptors offered by Brodaty et al (2003), although tiers 6 and 7 (the 'tip' of the Brodaty triangle) would be captured together within B4:

- 1 no dementia (M) – 93.4% of older Australians;
- 2 dementia no BPSD (D) – 39% or 63,000 people with dementia;
- 3 mild BPSD (DB1) – 29% or 47,000 people;
- 4 moderate BPSD (DB2) – 21% or 34,000 people;
- 5 severe BPSD (DB3) – 10% or 16,000 people;
- 6 very severe BPSD (DB4) – 0.9% or 15,000 people; and
- 7 extreme BPSD (DB4) – 0.1% or 200 people.

**Scenario:** Rose is aged 75. Since her husband died five years ago, she has lived with her youngest daughter (aged 39) who works full time and has three school-age children. Rose's other children live interstate. Two recent falls have resulted in osteoporotic vertebral fractures, and Rose also has osteoarthritis and mild cognitive impairment. Her daughter has begun to suffer from stress-related illnesses, and there are tensions with her son-in-law. Together with other factors, she is assessed by an ACAT as eligible for low care accommodation, and is offered a place in a new local facility, '**21<sup>st</sup> Century Homes**'.

Rose takes up residence in Lively Marigold (LM) Cottage and makes some new friends, including a former neighbour. She continues to drive to go to bridge games with her old friends, and for special events. A few years later, she is diagnosed as having mild dementia due to Alzheimer's Disease, and six months later a place becomes available next door in Lazy Daisy Cottage, where she transfers. Together with her family, she decides to sell her car, although she still enjoys regular shopping excursions utilising the Century bus with her Century friends. Older friends pick her up for special events. Her youngest daughter and her family continue to visit regularly. She finds support amongst residents as they talk together about dementia and its impact on their lives.

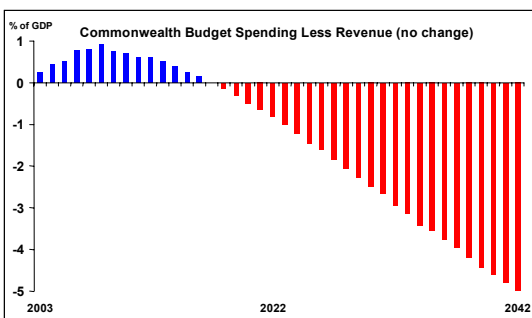
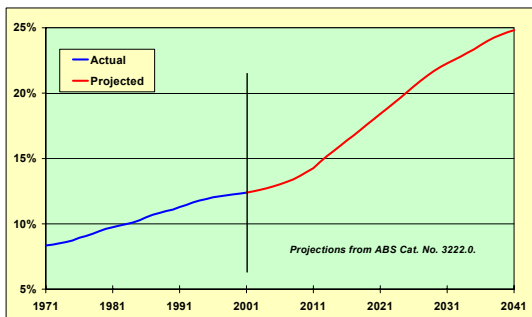
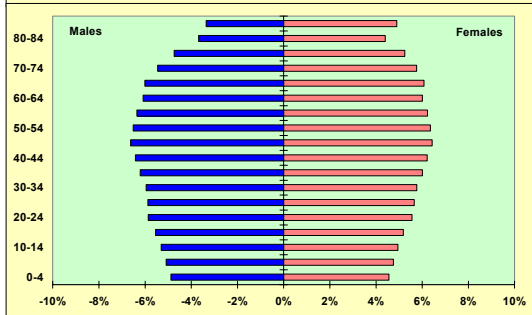
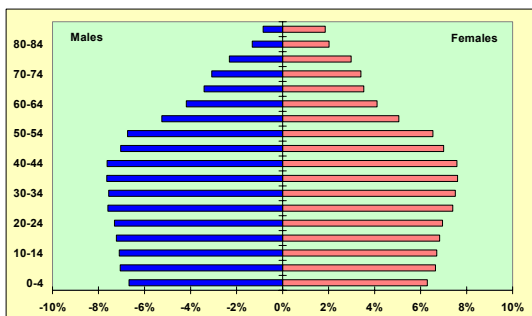
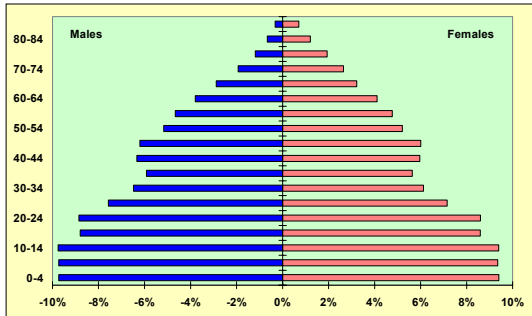
After her 81<sup>st</sup> birthday, Rose's wandering develops into agitated walking, she loses many language skills, and her GP and specialist describe her dementia as 'moderate' and her behaviours as 'B1'. She strides for some hours each day in the beautiful adjacent secure walking area, Serene Way. She also enjoys looking at photos with her family, and listening to her granddaughter playing the flute. However, she has been gradually developing some worsening behaviours that are disturbing other residents of Lazy Daisy. While some of these have been understood and addressed, others remain, including screaming at night (B3) and verbal aggression requiring frequent expert intervention (B2), for which family, staff and specialists have been unable to find any solutions.

Rose is provided with the next available place in an adjacent cottage, Little Dainty Bluebell. Her walking can be accommodated in a less accessible secure area, very similar to Serene Way. However, she becomes incontinent over the following year and the level of nursing that she requires necessitates a further transfer, at age 84, to a high care cottage for people with dementia and challenging behaviours, Heavenly Daffodil Bank. The aggressive behaviour and screaming stage gradually subside, becoming more infrequent and low-key. Then Rose falls and fractures her hip. After a 5-week hospitalisation, she has lost a lot of her mobility and ceases both walking and the disturbing behaviours.

Rose is resettled from acute care to Century, this time in Hydrangea Dusk cottage, where she spends her time in sedate activities including listening to music and massage therapy. At age 86, Rose develops a persistent infection and a palliative care specialist spends some time with her and her family during her final weeks. She dies peacefully at home in Hydrangea Dusk cottage with her daughter and granddaughters beside her.

### 3.2.6 Health financing and cross-cutting access issues

**Chart 15: Ageing in Australia: Population by age, 1971, 2001, 2041, dependency ratios and budget impacts**



For the 400 years prior to 1920, for which British data are available, the proportion of the population over 65 hovered around 8% of the total (Broe, 2002). From 1920, rapid population ageing in developed countries has begun. Australia has already seen significant demographic change – birth rates are lower, life expectancy is higher, family size has fallen and more people live alone. The change in the age structure from 1971 to 2001, together with the ABS projected change to 2041, is shown in the top three panels of Chart 15 at left. By 2041, people aged 65 and over will represent 25% of the population compared with 8% 30 years ago and just over 12% currently. The fourth panel of Chart 15 shows how this cohort of the population is expected to surge as a percentage of the total, increasing the ‘dependency’ ratio of older people to those of working age.

The implications of the demographic transition for health and aged care spending are substantial. Medical, hospital and pharmaceutical expenditures are all substantially higher per capita for older people than for younger people. Welfare (disability and carer) payments and aged care services will also burgeon. Moreover, in addition to demographic factors, changing technologies and baby boomer expectations will put sustained pressure on demand for services – both quantity and quality.

The impact on Federal budget balances, from both spending growth and a relative contraction of the work-force tax base, is shown in the final panel of Chart 15. The InterGenerational Report, released in May 2002, highlighted these topical issues, concluding that careful planning will be required to meet the future challenges, and accompanied by a sharp cut in the PBS budget.

Rather than targeting pharmaceuticals growth, which may well have a negative overall impact on national wellness as demonstrated in Section 3.2.2 above, more attention might better be directed at devising savings vehicles for health and ageing. These could include superannuation-type contributions (1-3% of income) acting as insurance against future residential or even home-based care costs, together with public safety nets to ensure equity of access. Other options could include incentives to extend unsubsidised private health insurance and review of copayments to ensure that marginal prices are sending appropriate demand signals.

The issue of pricing of aged care services is indeed a complex area, with subsidies for residential aged care currently under federal review. The May 2002 budget included a two-year (\$7.2m) review of pricing for RAC subsidies and also took a step in the right direction by delivering the election-promised \$50m indexed annually (totalling \$211.1 million over the four-year forward period) into RAC subsidies, as well as a sizeable package for capital development in rural and remote areas (see Table 24).

**Table 24: 2002-03 Federal Budget measures for residential aged care**

Measures	2002-03 \$m	2003-04 \$m	2004-05 \$m	2005-06 \$m	Total \$m
Capital assistance for aged care in rural & remote Australia	8.3	18.0	25.9	26.6	78.8
Increased RAC subsidies	51.2	52.2	53.3	54.4	211.1
Allowing new aged care residents a 28 day grace period from income testing	-	-	-	-	-
Review of pricing arrangements for RAC subsidies	3.7	3.4	-	-	7.2
Enhanced assessment of concessional residential status	-5.6	-13.2	-13.6	-13.9	-46.2
Sub-total residential care	57.6	60.4	65.6	67.1	250.9

However, existing Alzheimer’s Australia national programs appear under-funded. There has been no real increase in core DESP funding since 1997 and funding was cut with the implementation of DESP compared to its predecessor program funded under the National Action Plan for Dementia Care. Demand for services is outstripping supply, with long waiting lists for CEWT courses building up in many parts of the country. At current levels of funding, Alzheimer’s Australia services reach only 5-10% of the target group, with even lower penetration in rural and remote areas. Alzheimer’s Australia has an unparalleled reputation for delivering high quality and cost-effective dementia specific services, in part due to the use of well-trained and highly committed volunteers. As such, this delivery vehicle is being under-utilised – a critical mistake in the current climate. Bird and Parslow (2001), in reviewing Alzheimer’s Australia services, proposed that federal funding should be increased from \$4m to \$13m p.a. within three years. In 2001-02 funding was roughly \$5m.

Financing of dementia care will not be just an ageing issue. Being a younger person with dementia can be even more difficult and costly. Dementia care should not be linked exclusively to aged care. In addition to ACATs, DCATs (Dementia Care Assessment Teams) or even ADCATs (Aged and Disability Care Assessment Teams) should be available to include younger people with dementia, and suitable accommodation should also be available – perhaps cluster cottage style – for younger people. Another access issue relates to the fact that dementia is increasingly multicultural. Dementia policy and services should be increasingly multicultural too, and this requires specialist resources. In particular, there is a need for assessment tools that can be used for people from different backgrounds. Moreover, a lot more still needs to be done to destigmatise dementia.

There is scope for increased use of information technology in improved models of care. One example is the completion of a US pilot program for an Alzheimer’s Caregiver Support System (ACISS), recently announced by Healthvision Inc. ACISS is a web-based program including information and resources to support family caregivers and improve the care delivery process for key stakeholders. Communication between clinical professionals, caregivers and patients included videoconferencing and web-based messaging, moderated chats and forums. Caregivers could have their questions answered remotely by medical professionals, or communicate with their peers without leaving home.<sup>86</sup> General practice is another target area for IT-based solutions, as observed in Section 3.2.1 above.

A final consideration is the nature of generations of families and carers of the future. Many demographers are questioning whether the ‘selfish generations’ (baby busters, Generation X, Y and on)

<sup>86</sup> See [www.healthvision.com](http://www.healthvision.com)

will continue to provide the sacrificial home-based care of the past. It seems unlikely that attempts to tip the balance towards reliance on home-based and community services will continue to reap significant savings. There comes a time where, if families and carers are no longer prepared to provide voluntary services, home-based care may become as expensive – perhaps more so – than good residential care models. This should be recognised particularly in dementia care strategies of the future.

*The fate of many elderly people today is to spend their last years alone, ill and in poverty, segregated from a society that prefers to turn away from distressing sights. It is a society that believes we are responsible for creating our own success and has little patience with those on whom fate has bestowed anything less... Devotion is not a word that sits comfortably anymore. We see independence as our birthright. With the long shadow of Alzheimer's stretching in our direction, I wonder how we will cope with a partner who can no longer 'do his own thing' or 'get a life'. Will we care for each other in the way our parents have? And if we don't, who will?*

Hampson (2000)

**Summary:** Intergenerational planning needs to acknowledge the *need* for health and aged care spending to grow in real and relative terms, with strategies for successfully managing the change. These strategies will include minimising inter-generational transfers (fewer young people financing the growing number of elderly), maximising intra-personal transfers (savings schemes), coming to consensus on the private-public mix of care provision, improving models of care to promote both cost-efficiency and quality and providing safety nets for disadvantaged groups. Access for such groups, including people with younger onset dementia and people from culturally and linguistically diverse backgrounds, should also begin to be addressed now. More needs to be done to destigmatise dementia. Better use should be made of Alzheimer's Australia and of new information technologies in delivering services. We should not assume that future generations would provide the levels of voluntary care that previous generations have provided.

### 3.3 SCENARIO ANALYSIS OF VARIOUS INTERVENTIONS

This section provides some brief scenario analysis of the potential benefits and cost impacts of various interventions in dementia care. The cost analysis in the preceding chapter, and indeed cost studies around the world, have identified a number of principles in prioritising dementia interventions:

- (1) the financial cost of care for people with dementia, whether provided formally or informally, increases with disease severity – care needs to be taken not to just transfer financial costs to family carers (indirect costs) in an effort to reduce government (direct) costs;
- (2) the financial cost jumps considerably when the person is institutionalised. Policy-makers have concluded that more efficient outcomes are achieved by supporting home-based care (through services and financial assistance) for as long as possible, to lengthen the “optimal” level of care;<sup>87</sup>
- (3) any intervention that prolongs life will incur additional costs, in which case the most cost-effective interventions are ones that ‘buy’ the greatest number of DALYs (both through deferred mortality as well as reduced morbidity) for each dollar spent;
- (4) big savings in prevention only come from eliminating diseases which cause major disability, of which dementia is the giant – in which case research is the compelling investment area.

<sup>87</sup> In general, a net burden of care is placed on an informal carer if this exceeds the carer's “optimal” level, which may vary from person to person and often depends on the level of support that carers receive through financial assistance and service provision. More study needs to be conducted in Australia on optimal levels of care, which could perhaps be based on data from ACAT assessments. At the moment, many indicators seem to suggest that informal carers are either providing longer than optimal care levels or, to say the same thing another way, receiving insufficient services.



*“With indicated prevention, as pointed out above, prevention may actually cost more money. So why should we bother with prevention? The primary factor to consider is whether people have more satisfying years of life, which are free from disability, rather than saving the government money.”*

Jorm (2002)

Three scenarios are analysed – pharmaceutical interventions, participation in family carer support programs, and research resulting in a cure.

### **3.3.1 Pharmaceutical interventions**

Pharmacotherapies using cholinesterase inhibitors (CEIs) may have three important impacts:

1. permitting a delay in the institutionalisation of a person;
2. reducing the number of hours of informal care-giving required in the short run; and
3. improving the quality of life for patients and caregivers.

There are other beneficial effects – for example, using CEIs may save costs by reducing the use of other drugs such as antipsychotic medications, of reducing the need for other therapies (such as GP visits, hospitalisations) and of enabling people to continue working – however, these are not included here due to lack of sufficient large trial data.

As noted in Section 1.2.2, treatment of AD with CEIs delays progression of symptoms for nine to twelve months and possibly longer. CEIs have proved effective in 12, 24 and 30 week trials, some studies have shown that there is no loss of benefit after one year of treatment, and extension studies of placebo-controlled trials have shown that the effects of CEIs may last more than a year.<sup>88</sup>

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<sup>88</sup> Studies 1-7 show improvements in nine months of treatment, 8-11 in twelve months, and 12-13 more than twelve months.

(1) Farlow M, Gracon SI, Hershey LA et al (1992) “A controlled trial of tacrine in Alzheimer's disease” The Tacrine Study Group, *JAMA*, 268:2523–9.

(2) Rosler M, Anand R, Cicin-Sain A et al. (1999) “Efficacy and safety of rivastigmine in patients with Alzheimer's disease: international randomised controlled trial”, *BMJ*, 318:633–8.

(3) Tariot P, Solomon P, Morris J et al (2000) “A 5 month, randomized, placebo-controlled trial of galantamine in AD” *Neurology*, 54:2269–76.

(4) Rogers SL, Doody RS, Mohs RC et al (1998) “Donepezil improves cognition and global function in Alzheimer disease” *Arch Intern Med*, 158:1021–31.

(5) Thal L, Ferguson J, Mintzer J et al (1999) “A 24 week randomized trial of controlled-release physostigmine in patients with Alzheimer's disease” *Neurology*, 52:1146–52.

(6) Rogers S, Farlow M, Doody R et al (1998) “A 24 week, double-blind, placebo-controlled trial of donepezil in patients with Alzheimer's disease” Donepezil Study Group, *Neurology*, 50:136–45.

(7) Qizibash N, Whitehead A, Higgins J et al (1998) “Cholinesterase inhibition for Alzheimer's disease: a meta-analysis of the tacrine trials” *JAMA*, 280:1777–82.

(8) Rogers S, Friedhoff L (1998) “Long-term efficacy and safety of donepezil in the treatment of Alzheimer's disease: an interim analysis of the results of a US multicentre open label extension study” *Eur Neuropsychopharmacol*, 8:67–75.

(9) Winblad B, Engedal K, Soininen H et al (2001) “A 1 year, randomized, placebo-controlled study of donepezil in patients with mild to moderate AD” *Neurology*, 57:489–95.

(10) Raskind M, Peskind E, Wessel T et al (2000) “Galantamine in AD: a 6 month, randomized, placebo-controlled trial with a 6 month extension” *Neurology*, 54:2261–8.

(11) Mohs R, Doody R, Morris J et al (2001) “A 1-year, placebo-controlled preservation of function survival study of donepezil in AD patients” *Neurology* 57:481–8.

(12) Doody R, Geldmacher D, Gordon B et al (2001) “Open-label, multicenter, phase 3 extension study of the safety and efficacy of donepezil in patients with Alzheimer's disease” *Arch Neurol*, 58:427–33.

(13) Rogers S, Doody R, Pratt R et al (2000) “Long-term efficacy and safety of donepezil in the treatment of Alzheimer's disease: final analysis of a US multicenter open-label study” *Eur Neuropsychopharmacol*, 10:195–203.

In the following analysis, the work of independent and award-winning researchers Lopez et al (2002) in assessing the effects of these improvements on traditional milestones for AD have been utilised, and applied to the Australian situation. Lopez et al (2002), in an open label study, assessed cognitive function using the MMSE (endpoint less than 9), ADL using the Blessed Dementia Rating Scale (BDRS, endpoint 12 or more), and institutionalisation based on admission to a ‘nursing home’ (including US ‘personal care’ and ‘healthcare’ facilities ie, the equivalent of either low or high care Australian facilities). The results (see Table 25) showed that people who used CEIs:

- improved on all measures, with fewer than controls reaching the end-points (MMSE <9, BDRS 12+, institutionalisation);
- had significant difference in the rate of change in MMSE (16.3 the average for CEI users compared to 6.2 for non-users) – expected average decline 2.5 points for users and 3.5 points for non-users;
- had significantly higher BDRS scores for ADL (4.7 compared to 7.3 for non-users, and a significant difference in the rate of change);
- had significantly less institutionalisation (6% after three years compared to 41% for non-users) – this is supported by other studies, for example Knopman et al, 1996);
- no *significant* association was found between CEI use and time to death.

**Table 25: Outcomes of patients using CEIs compared to controls after 36 months**

	# CEIs	% total	# Controls	% total	X <sup>2</sup>	p value
BDRS > 12	35	26%	62	46%	13.1	<0.0001
MMSE < 9	38	28%	67	49%	11.7	<0.001
Institutionalisation	8	6%	56	41%	47.1	<0.0001

Source: Lopez et al (2002).

The research team concluded:

“Whereas short term benefits in cognitive and functional competence with CEI use are to be expected, it is the longer term outcome (the delay of entry into a nursing home) that demonstrates the powerful effect of these drugs. This suggests that physicians should be cautious in judging the medication response after only a few months of treatment, as the full benefits of CEI use take place over a longer time frame.”

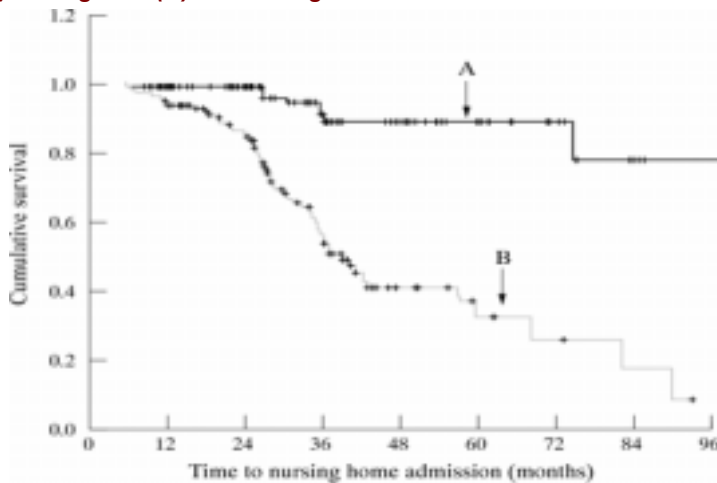
An implication for Australia is that the six-month review period required by the PBS for access to subsidised CEIs is too short. Furthermore:

“The fact that the use of CEIs delays time to nursing home admission and does not affect physical survival has important scientific and public health implications. The CEIs seem to allow patients to maintain relatively normal activities of daily living for a longer period of time, but to do so without significantly prolonging life.”

### 1. Delay in institutionalisation

Chart 16 illustrates the delay in institutionalisation, with the ‘survival rate’ for CEI users significantly higher even after 84 months. Clearly it is the area between paths A and B that represents the potential saving in institutional costs, with differences emerging from early on. It is interesting to note that in the first 24 months, nearly 20% of the control group had been institutionalised whereas *none* of the CEI users had found this necessary at this stage.

**Chart 16: Kaplan-Meier plot of time to nursing home admission among patients with AD (A) taking and (B) not taking cholinesterase inhibitors.**



Notes: A: n=135, B: n=135. 130 patients took donepezil, 22 took tacrine and were switched to donepezil, and 6 took rivastigmine. Nursing homes include the equivalent of Australian low or high care facilities. Source: Lopez et al (2002).

There are a number of possible approaches to modelling the effects of delays in institutionalisation due to use of CEIs. In submissions to the PBS, applicants are required to adopt a dynamic modelling approach where the number of people in the target group are identified; adjustments are made for those refractory to treatment, who die during treatment (eg, from a stroke or heart attack) or who for some other reason discontinue treatment; as well as individualistic (probability/risk) modelling of entry into residential care. Adjustments are made for changes in prevalence of the condition as well as the various impacts of the drug usage over time, with savings then identified in the initial and subsequent years until a steady state is reached.

An alternative approach, and the one adopted here, is to model steady state equilibrium positions with and without the intervention – like a ‘before’ and ‘after’ snapshot picture – but assuming the final steady state occurred in relation to the current prevalence pattern, to enable a ‘what if’ comparative analysis. Such an approach would not necessarily need to be limited to the populations for approved use as per PBAC rulings; in this case the modelling is applied to the population of all people with dementia, rather than just those with AD (the current PBS restriction) due to the growing evidence noted earlier that other non-AD forms of dementia may also respond similarly to treatment with CEIs. As such, this might be considered an ‘extreme’ scenario of maximum leakage from a PBS perspective.

Applying the Kaplan-Meier plot in Chart 16 above to a comparative steady state model, and as noted in Table 25 above, the difference between the CEI users and the control group was 35% at 36 months, or an average delay in institutionalisation of 12.71 months. This is also in line with the wealth of other literature noted earlier showing an average impact of improved symptoms of 12 months.

A delay in entry to residential care has three impacts – savings in residential care cost, increased expenditure on formal community care costs, and increased expenditure of informal care resources. Note this is *just* the *isolated* cost of not being in an institution, not the other advantages of wellness, which include lower carer burden and improved quality of life (being able to work, lower healthcare usage), which are addressed below. The costs of residential and formal and community care per person per annum have been estimated in Chapter 2.

A 12-month delay in institutionalisation would effectively mean that 12% of people with dementia (19,476 people) would not go into residential care that would have otherwise, as illustrated below:

Steady State 1	Community Care – 52%	Residential Care – 48%	8 years
	84,394 people	77,902 people	
Steady State 2	Community Care – 64%	Residential Care – 36%	
	103,870 people	58,427 people	

It is assumed that all people are treated in the community while their dementia is still in the mild to moderate stage, but people who are already in residential care due to reasons other than their dementia are not modelled as being treated with CEIs. This approach is adopted in order to quarantine the effect of the dementia treatment, rather than the more complex interactions of other factors also.

Results are depicted in Table 26. In this comparative static analysis, the Federal government would be \$597 million better off if residential care could be delayed for a year. Family carers, however, would be \$320 million worse off. Overall, there would be a net real economic saving of \$276 million (\$1,701 per person with dementia or \$14,178 per entry avoided) from delaying institutional care for one year.<sup>89</sup>

**Table 26: Savings, residential care deferred one year, Australia, 2002,**

Type of cost	Steady State 1			Steady State 2		Difference (\$m)
	\$/person p.a.	No. people	Total (\$m)	No. people	Total (\$m)	
<b>Residential</b>						
Residential care	36,547	77,902	2,847.1	58,427	2,135.3	712
<b>Community</b>						
Formal (Fed) comm. Care	2,554	68,435	174.8	84,210	215.09	-40
Informal community care	20,300	84,394	1,713.2	103,870	2,108.6	-395
Carer payments	7,307	44,394	324.4	54,638	399.3	-75
<i>Total</i>			2,212		2,723	-510
<b>Net difference</b>						(\$m)
<i>Savings per entry avoided (Fed)</i>		\$30,632		<i>To Fed government</i>		597
<i>Savings per entry avoided (total)</i>		\$14,175		<i>To informal carer*</i>		-321
<i>Savings per person with dementia</i>		\$1,701		<b>Total</b>		<b>276</b>

\* Not including gaps (residential care fees, community care payments). Source: Access Economics

From where does the net saving derive? It is speculated that residential care involves higher costs per unit due to additional capital and administrative costs – there are no tiers of management for the home carer. Certainly the finding is common to international studies. In Italy for example, Trabucchi and Bianchetti found savings of around US\$4,000 (A\$8,000) per person per annum through preventing a 4-point/year decrease in MMSE score in a year (the equivalent of CEI therapy). Leon et al (1996) estimate average total monthly cost of caring for an AD patient in 1996 was US\$2,306; US\$1,827 formal services and US\$479 of informal care, of which US\$2,029 can be saved if disease progression can be slowed – 88% of the total or nearly US\$25,000 per person p.a. Rice et al (1993) estimate that average annual formal carer costs for institutionalised persons

**Delaying residential care for one year saves government \$600m but makes family carers \$320m worse off.**

<sup>89</sup> Note that this is not the same as simply subtracting total community costs (\$510m) from residential care costs (\$712m) – which would suggest only a \$202m saving – because carer payments are a transfer cost. Delaying residential care causes \$75m to be gained by informal carers but lost to Federal government, thus the net effect is \$202m plus \$75m = \$276m.

with AD amounted to US\$42,049 per patient, more than three times the cost for non-institutionalised persons, suggesting savings in the order of US\$30,000 per entry avoided.

On this scenario there are likely to be additional savings due to the reductions in informal care hours required, to which we now turn.

**2. Reduction in hours of informal care required**

From the analysis above (Table 26) we saw that, if there were no change in health level, family carers bear the brunt of care in the community rather than in an institutional setting.

If delaying residential care for one year is accompanied by reduced care hours, everyone is better off.

However, because of the better outcomes in both cognitive function and ADL (nearly 50% better in each case), it is postulated that the hours of care required for the year of residential care avoided would actually be able to be costed at the level for mild dementia. The reduction in hours of informal care can be measured, once again adopting the replacement cost approach. This results in a 16.5 hour per week saving, using the University of Michigan Study results (see Sections 1.5.1 and 2.2.2), only 34% of the hours of care of moderate dementia. Thus the replacement cost would also be 34% and, in similar vein, the carer payments and formal care service hours required. The savings under this scenario are modelled in Table 27 below. Once again, it should be noted that this is a comparative static analysis of the whole population of people with dementia, rather than a dynamic analysis of just those eligible for PBS-listed drugs.

**Table 27: Savings, one year deferred residential care, symptoms improved, Australia, 2002**

Type of cost	Steady State 1			Steady State 2		Difference (\$m)
	\$/person p.a.	No. people	Total (\$m)	No. people	Total (\$m)	
<b>RESIDENTIAL</b>						
Residential care	36,547	77,902	2,847.1	58,427	2,135.3	712
<b>Community</b>						
Formal (Fed) comm. care	2,554	68,435	174.8	84,210	152.0	23
Informal community care	20,300	84,394	1,713.2	103,870	1,489.3	22
Carer payments	7,307	44,394	324.4	54,638	236.0	88
<i>Total</i>			2,212		1,877.3	335
<b>Net difference</b>						(\$m)
<i>Savings per entry avoided (Fed)</i>		\$42,257		<i>To Fed government</i>		823
<i>Savings per entry avoided (total)</i>		\$49,219		<i>To informal carer*</i>		136
<i>Savings per person with dementia</i>		\$5,906		<b>Total</b>		<b>959</b>

\* Not including gaps (residential care fees, community care payments). Source: Access Economics

Table 27 shows that, if residential care is delayed together with reduced care hours, equating to delaying the progression from mild to moderate dementia for one year, then net savings in a year are nearly \$1 billion – \$276m from delaying institutionalisation, and \$683m from reducing the extent of informal and community care services needed. Smaller packages are being provided to more people. The benefit here is that there is ‘Pareto optimisation’ – nobody is made worse off in buying an overall economic gain. Indeed, benefits under this scenario are now \$5,906 per person with dementia p.a. (closer to the Italian savings estimate also).



### 3. Improved quality of life

Finally, if progression of dementia to the moderate stage is deferred for one year, a person's quality of life is improved. Section 2.3 showed that the disability weightings for moderate dementia are 0.63, compared with 0.27 for mild cases. The disability burden of the severe cases does not change (still 48,689 people). However, more people move from the 'moderate' burden (now 22,072) into the 'mild' burden category (now 91,535). For 42,846 people, then, there is an extra 0.36 DALY each. Australia-wide, the gain is 15,425 extra years of healthy life!

Moreover, CEI use increases Australia-wide 'health-span' by over 15,425 DALYs per year

*"Within the next 20 years, Alzheimer's disease will likely surpass heart disease and cancer as the most costly disease in America... Medical interventions are becoming more promising, and with them comes the possibility that the economic burden of the disease may be lessened and, more important, clinical benefits realised. By improving cognitive function with pharmacotherapy, it is possible to reduce caregiver time, delay nursing home placement, and improve quality of life."*

Meek et al 1998, p72

And the cost of the treatment? Treating all Australians with mild dementia, as cases arise (ie, incidence), and assuming that the drug cost is \$160 per month, would yield a total cost of \$39m in the first year. However, to reach the steady state equilibrium as modelled above, the ongoing annual drug cost would be \$139m. In terms of cost: benefit ratios, there would be a return to Federal government of around 6:1, and an overall return of at least 7:1.

Returns to investment in CEI use are 7:1, plus a 13% increase in healthspan for people with dementia

#### 3.3.2 Support for family carers

Benefits of support programs have been researched in a number of studies. One study, the Mittelman study from New York, showed that family carers of people with AD who received family and individual counselling were able to give care for almost a year longer than those in the control group. In Australia, Brodaty has shown that involvement in a ten-day training course, with follow-up from a key worker for at least twelve months, lowers levels of stress and depression in family carers.

The cost of the Early Stage Dementia Support and Respite Program in Australia, in terms of providing 1:1 support, is estimated as \$37.50 per hour provided or, assuming the equivalent of weekly one-hour sessions as the model of care, \$1,950 per person per annum. Alzheimer's Australia has suggested in its 2003-04 Budget Submission that spending of \$300,000 is indicated to extend this program in the community to meet current demand. This level of funding would provide 8000 hours of care or help 154 people according to the scenario modelled here. From the previous scenario, we know that savings per nursing home entry avoided would be \$14,175 after compensating families and carers, even if there were no net benefit to health. This saving for all 154 people would result in overall savings of \$2.18m, or a cost: benefit ratio of 1:7. This might be taken into consideration in the current evaluation of the program, and might even suggest a larger budget for the program than the proposed additional \$300,000. The outcomes are summarised in Table 28.

**Table 28: Returns to Support Spending, ESDSRP, 2002**

ESDSRP new spending	\$300,000
Hours of support	8,000
Hourly cost	\$37.50
Per carer 1hr/wk, 52wks	1,950
Numbers of people helped	154
Savings per entry avoided	\$14,175
154 people not institutionalised	\$2,180,837
<b>Return to \$1 p.a.</b>	<b>\$7.27</b>

Returns to investment in support programs may also be in the order of 7:1, plus increased in healthspan for family carers

**3.3.3 Research resulting in a ‘cure’**

The magic bullet. It may not be as long a shot as it appears<sup>90</sup>. Hatfield, Sonnenschein and Rosenberg (2000) summarise the research of Murphy and Topel on the economic value of investment in medical research over the longer term. Some of their findings include:

- roughly one third of the total health savings are a result of medical research that led to new drugs and treatment protocols, with 3:1 consistent average long term returns;
- the order of magnitude of savings for ‘big’ diseases are huge – the savings from prevention and treatment of cardiovascular disease over the 1970s and 1980s were US\$1.5 trillion, representing an average return of US\$500 billion per annum, while research success that spared just 1 cancer death in 1000 would be worth US\$46 billion p.a. (the total US research budget – private and public is US\$45 billion);
- small programs can also reap exceptional returns – for example a 17-year program which invested US\$56 million in research on testicular cancer led to a 91% cure rate and ongoing annual savings of US\$166m;
- the economic value of longevity rises as society becomes more prosperous and the value of curing or preventing chronic diseases of ageing such as dementia, is rising as average age of the population rises;
- progress in research against one illness increases the value of progress against another; and
- these estimates are purely financial – they exclude the benefits of increased healthspan.

Applying these principles to dementia research in Australia, the case for higher funding levels is even more compelling. Table 29 summarises the issues. The real cost of dementia is \$5.6 billion, while our current Federal investment in finding a ‘cure’ is around \$2.5m p.a. (see Section 3.2.3). This is compared to a suggested investment of \$49m p.a., which would bring Australia in line with current US spending. On the basis of the long term average for medical research investment, \$1.9 billion of research would be required to find a ‘cure’. At the current investment level, we won’t find a ‘cure’ for 748 years. If we spent at target, we would find a ‘cure’ by around 2040. The magnitude of health savings in current dollars would be around A\$4 trillion.

<sup>90</sup> It should be noted in this scenario that what is being modelled is the extreme case of a prevention or treatment being discovered that is able to completely eradicate dementia, as with polio, and such as might be promised by a future ‘vaccine’. In reality, the multi-causal aspects of dementia diseases might mean that ‘cures’ form a spectrum of outcomes including disease reversal or significant delay of onset, substantial reduction of symptoms and extension of quality life through improved management (as with AIDS), and the like.

**Table 29: Returns to research investment in Australia**

Real cost of dementia (\$m)	\$5,608
Investment in cure (current)	2.5
Investment in cure (target)	49
Ratio of returns	3:1
Implied research level required (\$m)	\$1,869
Years to cure (current)	748
Years to cure (target)	38
Difference in years	710
Potential cost savings (\$m)	\$3,979,200

**A cure by 2040?**  
**Increasing research**  
**to \$49m p.a. could**  
**save Australians**  
**\$4 trillion in future**  
**health costs**

**3.3.4 Summary of scenario analysis**

1. **Delay of institutionalisation** for 12 months saves the Federal government \$600m but makes families and carers \$320m worse off, with net overall savings of \$14,175 per entry avoided;
2. **Delayed progression of illness** – mild rather than moderate – together with delayed institutionalisation is preferred, as families and carers would be \$136m better off and the Federal Government \$823m better off, with overall savings of \$49,219 per entry avoided.
3. **use of CEIs** achieves both the above outcomes with returns of 7:1 on investment, as well as saving 15,425 DALYs – a 13% increase in healthspan for people with dementia.
4. **support programs for family carers** – such as delivered through the ESDSRP, also accrue returns of around 7:1 on investment, together with valuable health outcomes for families and carers.
5. **research resulting in a cure** – increasing research funding to \$49m p.a. from the current 2.5m could generate a cure by 2040 and save Australians \$4 trillion in future health costs.

## 4. OPTIONS AND CHALLENGES

*“While much has been done to assist people with dementia and their families and carers, much remains to be done. Given the scale and progression of the epidemic, simply doing whatever the community is already doing means going backwards and going backwards at an ever-increasing rate.”*

Alzheimer Australia’s submission to the 2003-04 Federal Budget

### 4.1 SETTING THE SCENE

#### 4.1.1 National Action Plan for Dementia Care

This section briefly outlines where we have come from in strategic planning for the dementia epidemic. The five-year National Action Plan for Dementia Care (NAPDC) was instituted in 1992. It set a strategic direction for dementia care designed to strengthen the capacity of the aged care system to better meet the needs of people with dementia and their families and carers. Rather than advocating a separate stream for dementia care services, it aimed to integrate the various aspects of dementia care through the aged care sector and programs. The Action Plan set targets and actions for achievements between 1992-93 and 1996-97 in seven key areas, namely:

- diagnoses and assessment;
- services for people with dementia;
- services for families and carers of people with dementia;
- quality of service;
- community awareness;
- research and evaluation; and
- policy and planning.

Midterm review of the NAPDC identified the priority need for a more coordinated approach to dementia care training for all staff working in residential aged care facilities. The National Residential Dementia Training Initiative (NRDTI) was thus established to provide systematic training for staff in Commonwealth funded residential aged care facilities in order to improve dementia care practice. The NRDTI also aimed to facilitate the longer term capacity of the aged care industry to sustain dementia care training beyond the Initiative.

Other challenges highlighted by the NAPDC included special problems in rural and remote communities and continued harnessing of political will, particularly at State and Territory government level. The NSW Government implemented the five-year NSW Action Plan on Dementia 1996-2001 and has recently released the next plan “*Future Directions for Dementia Care and Support in NSW 2001-2006*”.<sup>91</sup> Victoria has also produced an excellent policy statement, “*Dementia Care and Support in Victoria: 2000 and Beyond*.”<sup>92</sup> All States and Territories have to some extent either produced dementia-specific strategic plans and/or incorporated dementia aspects into mainstream service planning.

The 1997 Aged Care Reforms were introduced in part to improve the structural service delivery for older Australians with complex physical, mental and psychogeriatric needs. Fine-tuning continued through the National Strategy for an Ageing Australia<sup>93</sup> (2001), towards the thematic goal of ‘world class care’.

<sup>91</sup> The NSW strategy is at <http://www.add.nsw.gov.au/PDF/Future%20Directions%20CD%2010.9.pdf>

<sup>92</sup> Victorian Government Department of Human Services, November 2000, available on [www.dhs.vic.gov.au/acmh](http://www.dhs.vic.gov.au/acmh)

<sup>93</sup> The National Strategy is available on [www.health.gov.au/acc/foa/documents/pdf/nsaabook.pdf](http://www.health.gov.au/acc/foa/documents/pdf/nsaabook.pdf)

#### **4.1.2 Aged care reforms and the Two Year Review**

Professor Len Gray reported specifically on dementia care in the Two Year Review of Aged Care Reforms, which was finalised in 2001. He stated that the government is working towards a national dementia policy framework, with first steps being the August 1999 Dementia Forum, additional DESP funding, expansion and enhancement of respite services including Carer Respite Centres, carer training, new funding for the Early Stage program and the national helpline, growth in PGUs and training in dementia care for people from diverse cultural and linguistic backgrounds.

He noted that the former Personal Care Assessment Instrument (PCAI) and the Resident Classification Instrument (RCI) had not adequately recognised the amount of staff time required to care for residents with dementia, as also recognised by Rosewarne et al (1997). Also, because funding levels were not linked to the severity of behavioural problems of people with dementia and did not recognise the resource intensive nature of dementia-appropriate care, he concluded that “a major disincentive to caring for these residents was built into the system” Gray (2001, p214). Gray noted that Cuthbertson, Lindsay-Smith and Rosewarne (1998) found that the ‘new’ Resident Classification Scale (RCS) introduced in 1997, increased funding for residents with cognitive impairments and behavioural needs by some 20%.

While in theory this might be true, critics argue that it does not occur in practice and that, as validated by the RCS assessors, the RCS is *hostile* to dementia care. This is because questions 8-14 of the RCS, the behaviour questions that most likely relate to dementia specifically, constitute as little as 16% of funding and that Q 8 and 12-14 are four of the six most *downgraded* questions by validators. Moreover, *negative* incentives occur since the system rewards perverse behaviours, rather than rewarding quality care that effectively prevents and manages those behaviours.

The Two Year Review noted “some participants considered that access to care for people with behavioural problems has *not* improved, as some providers are reluctant to admit residents who exhibit difficult behaviours and are unable to provide secure accommodation.” Gray (2001) also concluded that:

- there is a lack of data regarding dementia in residential care, although proxies can be derived from RCS weighted scores of those who *probably* and *possibly* have dementia; these data showed that 91% of residents in high care homes and 58% in low care homes fell into either category, including almost *all* RCS1 (99%) and RCS2 (95%) residents;
- the consultation process highlighted a lack of specialised and secure accommodation for people with moderate to severe dementia, and insufficient financial support for providers to supply it;
- there was insufficient data to comment on the need for secure and segregated accommodation, although noting that the government identified priority pockets of need for dementia-specific care for the first time in the 2000 capital works Approvals Rounds;
- priority in Approval Rounds and the changes in the RCS will not necessarily deliver an appropriate quantum of dementia specific homes in every region of Australia.
- *It is recommended that further investigation be undertaken into the needs for and provision of accommodation and care options for people with dementia. Such an investigation should include a focus on infrastructure and options for addressing identified deficiencies.*

For a two-year review, this single recommendation for ‘further investigation’ is insubstantial. One would hope that such investigation was ongoing anyway. In the discussion, there also seems to be little appreciation of the problems related to the various capital and recurrent funding issues for high care and low care facilities respectively or the problems in the RCS, which had the opportunity to identify and provide for dementia behaviours and environments and did not. Rather, although the ACAT/RCS



instruments have improved on the former PCAI/RCI instruments, they have not addressed the key issues as they continue to classify and weight needs primarily in terms of nursing needs, provide insufficient data for the evaluation of dementia outcomes, and fail to address the issues associated with financing capital costs. The review also failed to look at particular non-residential care needs for people with dementia.

The fairly blunt industry response to the review is summarised in Aged and Community Services Australia (2001), including a number of 'real world aged care economics' examples and case studies precipitating negative returns on investment, concluding (p10) that:

"The Report... leave[s] the reader with the view that the reforms have fixed all the significant problems in aged care and that all of the measures introduced since 1997 are working smoothly and effectively. As this Industry Response has shown, nothing could be further from the truth.

The aged care industry is fast reaching a crisis point in terms of its ongoing viability. It is unable to gain access to the capital required to make necessary building improvements or to finance the new beds needed. The industry is drowning in an increasing volume of red tape and is facing increasing difficulty in recruiting staff it needs to provide quality care...

Older people still suffer the consequences of poor coordination between the health and aged care systems. They still experience significant problems in gaining access to the services they need. They still suffer from failures in the quality of care. Older people deserve better.

Resting on its laurels is not a viable option for any Federal Government. That should be the real conclusion of the Two Year Review of Aged Care Reforms and the basis for a genuine Government response."

In its response to the Two Year Review, the government accepted the recommendation and pointed to:

- Claims that average funding per dementia resident had increased 124% since 1997 (no data provided, and no description of how dementia residents were identified);
- \$92.5 million over 4 years to expand respite for families and carers of people with dementia; and
- establishment of a working group to consider the care and accommodation needs of people with dementia.

The Report of the Working Group on Dementia Specific Aged Care has just been released, concluding that there is scope for improvements to accommodation and care options across all tiers of dementia needs. Specific conclusions and departmental responses are<sup>94</sup>:

1. *More research and evaluation is needed on effective care services for people with dementia.*

Response: Making services more effective for people with dementia will be considered further in the Community Care Review.

2. *Joint Commonwealth/State/Territory action is required for people with extreme or severe behavioural and psychological symptoms of dementia.*

Response: The Commonwealth Government will discuss options with the State and Territory Governments.

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<sup>94</sup> Department of Health and Ageing (2002b), p21.

3. *While appropriately structured residential aged care services are sufficient for many people with dementia, planning should take account of the need for dementia specific care, both residential and community.*

Response: The needs of people with dementia will be considered in the Review of Pricing Arrangements of residential aged care and the current review of RCS funding options.

4. *Access to respite care for people with behavioural and psychological symptoms of dementia needs to be enhanced.*

Response: The needs of people with dementia will be considered in the Review of Pricing Arrangements of residential aged care and the current review of RCS funding options. It should also be noted that the 2002-03 Federal Budget provided \$10m for Commonwealth Carer Respite Centres to top-up payments to facilities offering dementia specific accommodation. Additionally, the 2002 Budget includes \$10 million over four years to expand the Psychogeriatric Care Units to achieve national coverage as a Commonwealth only program.

5. *A greater emphasis is needed in community care on the provision of dementia specific programs delivered by trained staff.*

Response: This will be considered further in the Community Care Review.

6. *There are gaps in the early intervention services for people with dementia and their families. Depending on the outcomes of the evaluation, the Alzheimer's Association Australia Early Intervention project (funded by the Commonwealth) may be a model for such a service.*

Response: This will be considered in the evaluation of the Early Stage Dementia Support and Respite Project.

## **4.2 THE FUTURE VISION**

Disease and disability associated with dementia are not inevitable consequences of ageing. The challenge of the dementia epidemic that is now, in 2003, becoming increasingly evident, is to attain declining disease and disability rates amidst a steep rise in the number of older people. The task is urgent. But there is broad scope to implement a positive agenda that can sustain an effective response over the coming decades.

In Australia, our mental health and broader health goals should be aimed primarily at *increasing 'healthspan'* – years of healthy, active life expectancy. To this end, we must adopt a longer term national vision about future action – not just in terms of disease management, but also in terms of action that government, academia and the private sector can jointly pursue to prevent and ultimately cure dementia.

A national vision requires a *nationally coordinated approach*. Commonwealth and State and Territory governments must come together with health professionals, people with dementia and their families and carers to acknowledge and plan for the demands of an illness that is poised to become Australia's number one health issue in the next two decades. Secure political commitment and consensus among stakeholders is essential.

With the first wave of baby boomers commencing retirement in 2005, the demographic transition is now firmly underway. In that fiscal context, it is crucial to not simply put more money into ineffectual systems but rather to shift health spending from acute to *chronic care models* to maximise returns from limited resources and to utilise evidence based approaches. Moreover, many interventions to date have been suboptimal, if not myopic, focusing on direct costs rather than the enormous benefits of investments in

wellness. *Whole economy analysis*, including impacts on the labour market and other sectors, must be considered from now on in policy development for healthy ageing and dementia care.

Strangely, the enormity and priority of the dementia epidemic has not yet been acknowledged in national policy making. Dementia is already intricately linked with recognised national health priorities including cardiovascular disease, diabetes and depression, and it is the mostly costly area of mental health. Dementia prioritisation, and a *national strategy to realise the vision*, is long overdue.

Five key elements of the future strategy must involve:

- a significant investment in research for cause, prevention and care;
- early intervention through improvement in diagnosis, and the provision of cost-effective pharmacotherapies;
- comprehensive provision of support, education and respite services – in place in the community as far as is optimal;
- quality residential care, appropriately financed, that are centred on the person with dementia and their family/carer; and
- provision for special needs, including people with younger onset dementia, people with special BPSD needs, people from culturally and linguistically diverse backgrounds, indigenous Australians and people in rural and remote areas.

If, starting today, we embark on such positive strategies, Australia can lead the way in effectively and smoothly managing the dementia epidemic transition.

*“Thanks to the efforts of thousands of carers, the last 20 years have seen the stigma of dementia at best reduced but not removed. A positive approach to planning dementia care now will ensure that in twenty years time the quality of life of people with dementia, their families and carers will be much improved – a society truly committed to the prevention of dementia. That is the vision of the Alzheimer’s Association Australia.”*

Alzheimer’s Australia,

Submission to the Parliamentary Inquiry on the Ageing of the Australian Population, 2002

## 4.3 STRATEGIES AND RECOMMENDATIONS

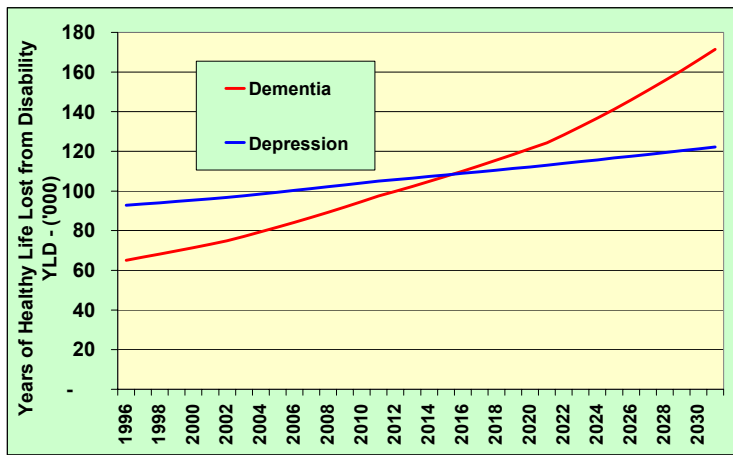
### 4.3.1 *Prioritisation of dementia*

Because of the impact of demographic ageing and the importance of dementia in overall health costs and disease burden, dementia (and the nexus between ageing and mental health more generally) must be incorporated in Australia’s priority setting for health and ageing.

Most telling is that dementia, after depression, is already the second largest cause of disability burden in Australia (ahead of diabetes, asthma, osteoarthritis and the other health priority areas), and it is growing much faster than depression so is set to become the number one cause of disability burden by 2016.

Dementia should be a national priority. It is set to become the Number One cause of disability burden in Australia by 2016. It will touch many of us directly or indirectly.

**Chart 15: Burden of disability of dementia and depression, ‘The Big Two’, 1996-2031**



Source: Access Economics projections, based on AIHW and ABS data.

The issue is how and where to prioritise. Dementia does not fit completely comfortably in either the aged care or mental health portfolios. Currently dementia care is funded primarily through aged care programs and the risk of dementia increases sharply with age. Moreover, some stakeholders are not comfortable with the mental health categorisation of dementia in international and disease classifications given remaining stigma.

Although mental health is one of Australia’s seven national health priorities, together with cardiovascular disease, cancer, injuries, diabetes, asthma and chronic musculoskeletal disorders (notably arthritis and osteoporosis), the National Mental Health Strategy has not embraced dementia. The mental health care resources list on the federal departmental website has 666 words, none of which is ‘dementia’ or ‘Alzheimer’s’ (see [www.mentalhealth.gov.au/resources/](http://www.mentalhealth.gov.au/resources/)). Searching the mental health home page for the word ‘dementia’, yields no hits at all ([www.mentalhealth.gov.au/index.htm](http://www.mentalhealth.gov.au/index.htm)).

Whatever decision is taken on the most effective point of coordination of planning dementia, it is clear that a whole of government approach is needed. This is because dementia care is so broad ranging, covering aspects of aged care, community care, residential care, medical services, psychiatric and specialist services, pharmaceuticals, workforce and housing.

**Recommendation 1:** *Dementia should be a national health priority. Because dementia issues are so broad ranging – covering aspects of aged care, community care, residential care, medical services, psychiatric and specialist services, pharmaceuticals, workforce, housing, research, technology, finance and so on – a coordinated sector-wide approach needs to be adopted in addressing these recommendations. It is vital that dementia initiatives are no longer lost between bureaucratic divides or governmental tiers, being referred from one review to the next without concrete action. Rather, priority should be accorded within public sector programs, resources and funding in a coordinated and comprehensive manner.*

*The current National Mental Health Strategy review and the Residential Aged Care Pricing Review should provide concrete proposals for addressing the issues raised in this report. Consideration should be given to including a central coordination point for future ongoing dementia planning and care, perhaps as part of a more strategic approach to neurodegenerative disease.*

### 4.3.2 Research

**Recommendation 2:** *The funding of dementia research should form an essential part of the government's response to the dementia epidemic, as well as forming part of a more general reprioritisation of health research resources on the basis of projected prevalence, costs and disease burden. In view of Australia's international comparative advantages in health research investment, as well as the potentially enormous cost-effective returns (potentially saving up to \$4 trillion in Australia in long term health costs), urgent action should be taken to substantially boost the level of research funding for dementia including:*

- Official research funding for dementia should be increased to \$49m per annum within three years, with prioritisation of specific projects determined in conjunction with Alzheimer's Australia.*
- Research priorities should be directed towards:*
  - **Cause:** *Understanding of the biomedical causes of dementia, including epidemiological (population-based) medical risk factors and public health research<sup>95</sup>;*
  - **Cure:** *Measures that prevent or postpone the onset of dementia, or that slow or reverse disease progression<sup>96</sup>;*
  - **Care:** *Effective models of care (best clinical practice) for people with dementia, including ways to enhance primary care, dementia services (as per Section 3.2.5) and effectiveness of training interventions.<sup>97</sup>*
- Research should be collaborative and multidisciplinary, including the interaction of other conditions on dementia (eg, diabetes), and the interconnections between different types of dementia, with emphasis on prevention, healthy brain ageing and effective quality care.*

### 4.3.3 Prevention and early intervention activities

**Recommendation 3:** *Promotion of dementia prevention activities should be initiated, targeting the community and health professionals (particularly in primary care), possibly in conjunction with other stakeholders including consumers groups (such as the Heart Foundation) and official bodies, including:*

- addressing cardiovascular risk factors – reducing hypertension, cholesterol and homocysteine (folate) and anti-platelet treatments;*
- promoting good diet, exercise, quitting smoking, and drug and alcohol programs as dementia prevention activities as well as promoting health generally;*
- promoting ongoing awareness to reduce other dementia risk factors such as head trauma (eg, seat-belts, helmets etc), occupational hazards (eg, exposure to electromagnetic fields) and others as revealed or confirmed by ongoing research.*

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<sup>95</sup> This research, together with awareness campaigns, has enabled diseases such as lung, skin and breast cancer to be seen as conditions with preventable elements subject to a public health approach.

<sup>96</sup> Specific research priorities might include amyloid-based treatments (including immunisation), new drug treatments (including with memantine), anti-inflammatories, oestrogen therapies, anti-oxidants and nerve growth factor supplementation.

<sup>97</sup> Specific priorities include research on diagnosis, effects of care standards (community care, long term care, terminal care, care needs and planning), carers' support, alleviating distressing behavioural symptoms and pain for non-verbal patients, medication for nursing homes and research into true levels of awareness (insight) in dementia (Maller and Rees, 2002).



#### **4.3.4 General practice**

**Recommendation 4:** To address the gaps and unmet need in current service provision, measures to enhance GP services should be initiated or expanded, including:

- GP education and support in implementing models of care that include early diagnosis, care planning and information about the support available for people with dementia, their families and carers;
- GP training and appropriate remuneration for ongoing management of dementia;
  - introduction of a program for ‘dementia-accredited’ GPs
  - review the rebate scheme for GPs visiting patients in residential care;
- teleconferencing and other initiatives to support more isolated GPs in diagnosis and treatment.

#### **4.3.5 Other medical and acute care services**

**Recommendation 5:** To address quality, cost and workforce issues in acute care, measures are required to:

- ensure quality person-centred dementia care is available throughout the acute care system;
- prevent admission to the acute care system through better treatment of people with dementia in their own (family or residential) home, including possibly psychogeriatric services to complement ACATs;
- assessment of acute care hospital waiting times for transfer into residential facilities, relative costs and potential mechanisms for reducing these, such as ‘Innovative Places’ or similar models; and
- measures to enhance recruitment, retention and training of nurses in dementia care, possibly utilising moneys from the \$47.5m (2002-03 to 2005-06) announced last budget for aged nursing;
- workforce measures to increase training, recruitment and retention of specialist geriatricians; and
- greater investment in specialist referral services (such as memory clinics) to support GPs in diagnosis and management of people with early stages of dementia.

#### **4.3.6 Pharmacotherapy**

**Recommendation 6:** Affordable access to medications appropriate to their diagnosis should be expedited for all people with dementia. Current PBS arrangements should be replaced by a simpler access regime comprising:

- diagnosis confirmation by a specialist or by a dementia-accredited GP;
- ongoing access predicated on best clinical practice, which might involve, for example:
  - regular monitoring of broad patient outcomes such as maintenance or improvement in cognition and/or social functioning, including for people who have non-Alzheimer dementia;
- access to telephone approval of authority scripts.

Pharmaceutical expenditures should not be seen as a cost but rather as an investment in wellness:

- PBS cost-cutting measures that are not evidence-based should be avoided;

- *subsidies should encourage pharmaceutical interventions for dementia based on Clinical Practice Improvement studies, and noting that this study shows returns to investment in cholinesterase inhibitors of 7:1 due to delays in institutionalisation and reduced carer burden, together with improved quality of life;*
- *treatment of agitation in dementia and access to anti-psychotics should reflect existing evidence; and*
- *longer term differences, rather than just those limited to six months, should be considered.*

#### **4.3.7 Home and community support services**

**Recommendation 7:** *While much has been done to enhance home and community services in recent years, remaining priorities include:*

- *a one-off 20% increase in the Home and Community Care (HACC) program funding;*
- *6% growth per annum in HACC funding (to cover demographic ageing based prevalence increases) plus an indexation amount that more adequately covers increased costs in service delivery, to be negotiated in consultation with key stakeholders;*
- *greater inclusion of the voluntary sector (including families and carers) in the formulation and implementation of policy with respect to people with dementia and their families and carers.*

#### **4.3.8 Families and carers**

**Recommendation 8:** *Family and carer support, education and respite remain an ongoing challenge, as well as one of the most important aspects of managing the epidemiological dementia transition. A long term strategy is required to be developed by key stakeholders. There have been advances in family and carer services in recent years, but current evidence suggests that care support remains sub-optimal (ie, an undue burden on families and carers). Additional measures should include:*

- *consideration of “optimal” informal care levels with a view to setting guidelines and targets for long term planning purposes;*
- *additional recurrent funding to promote best practice in respite care including:*
  - *incentives for implementation and diversification of ‘carer friendly’ models of respite care, including facility-based respite services, building on pilot studies; and*
  - *respite services which cater for people with the specific behavioural and psychological symptoms of dementia (BPSD);*
- *applying best-practice carer education and support models identified by research, pilots, trials and evaluations which, as with cholinesterase inhibitors above, show potential average returns around 7:1;*
- *improve incentives to encourage increased employment participation and retention of families and carers, including flexible work practices such as part-time home-based work, work-based adult day programs, workplace dementia awareness and destigmatisation.*

**Please remember this:** *Community care is good policy – but only if it acknowledges that the home-based care of a person with dementia can be a skilled, exhausting, costly, long-term, lonely job for the person doing the caring. It must be properly resourced to be accessible to all Australians.*

*Alzheimer’s Australia (2001a)*

#### **4.3.9 Strengthening community services provided through Alzheimer's Australia**

**Recommendation 9:** Any strategic national plan to address the dementia epidemic in Australia must include nationally consistent and longer-term funding arrangements between governments and the voluntary groups providing services to people with dementia, notably Alzheimer's organisations, which are cost-effective and high quality delivery vehicles, due in part to the dedication of volunteers. Long term recurrent funding arrangements need to be negotiated with Alzheimer's Australia, including:

- a one-off increase in funding for Alzheimer's Australia from \$5m pa in 2001-02 to \$13m by 2003-04, with annual indexation reflecting both cost-price factors and increases in numbers of older people, to enable:
  - (i) extension of Carer Education and Workforce Training (CEWT) courses, accredited courses for workers in residential care, and to meet special needs of families and carers;
  - (ii) increased Dementia Education Support Program (DESP) funding for national expansion of counselling services, including additional full time counsellors in NSW and Victoria and part time staff in other States and Territories;
  - (iii) expansion of the Early Stage Dementia Support and Respite Program (ESDSRP) (currently being evaluated), and/or additional funding provided for a new program for support and respite for people with mid-stage dementia, based on the results of successful pilot projects undertaken by State and Territory organisations;
  - (iv) additional funds to meet the specific requirements of people with dementia and their families and carers with special needs, including people from culturally and linguistically diverse backgrounds, indigenous people and people with low levels of literacy, and people in rural and remote communities;
  - (v) expanded information resources projects including on Down's Syndrome and dementia;
  - (vi) dedicated funding to build infrastructure for national data collection.
- an expansion of psycho-geriatric units (PGUs) has been funded by the Commonwealth. This will follow a review of the operation of current projects. The expansion of PGUs on a national basis using a consistent behaviour advisory model and focusing on meeting the needs of staff working with people with challenging behaviours would form a useful part of the overall service network.

#### **4.3.10 Residential care**

**Recommendation 10:** Residential dementia care remains problematic. In general, the principles of ageing in place and including dementia care within mainstream aged care are desirable, however the mechanisms for addressing identified constraints need to be addressed within the context of the current Pricing Review. Priorities include to:

- incorporate behavioural and environmental recommendations in Aged Care Assessment Team (ACAT) assessments, so that people with dementia and the nature and stage of that dementia are identifiable;
- revise the Resident Classification Scale descriptors to accord better with ACAT assessments, reflecting behavioural and environmental care needs as well as nursing and personal care needs, so that people with dementia and the nature and stage of that dementia are identifiable;
- in the context of the federal Review, and in close consultation with providers and other key stakeholders, review and make recommendations to implement changes to subsidies and possibly

accommodation bonds and other funding vehicles in ways that remove the disincentives to provision of quality dementia residential care, in particular addressing:

- capital constraints to high care facilities for people with dementia, including with BPSD; and
  - recurrent funding constraints to low-care facilities for people with dementia/BPSD.
- joint review by government, providers and stakeholders of the long term capital requirements for new dementia facilities based on better models of dementia care, with consideration of a full range of finance vehicles including insurance mechanisms;
  - change the residential care planning guidelines to ensure that all facilities have the capacity to care for people with dementia and that at least 10% of residential care places are dementia specific for those with special support needs;
  - assess supply and demand factors driving growth in overall numbers of places and ensure that supply growth is adequate and sustainable to meet demand growth over the longer term;
  - promote and fund new aged care facilities built on the cluster campus model on a provider-government partnership basis;
  - extend the number and diversity of newer models of quality care to help residents with dementia, with ongoing cost-benefit evaluation in particular in relation to quality of life;
  - increase ongoing nursing training in dementia-specific and quality person-centred care principles, ensuring that all residential care staff have completed formalised competency based training at the Certificate III level in Aged Care, and understand the needs of people with dementia and how that impacts on service delivery;
  - increase specialist geriatrician input into diagnosis, management and training;
  - introduce government support for the cost of staff training in facilities with limited financial resources or whose ability to provide staff training is otherwise constrained;
  - ensure guidelines are developed that identify appropriate staff to resident numbers linked to dependency that address understaffing;
  - tighter accreditation and monitoring of standards to promote quality care, with restrictions placed on chemical and physical restraint practices;
  - review of nursing and personal care worker remuneration;
  - improved access to specialist behaviour advisory services;
  - greater access to care for people with dementia with serious psychiatric symptoms, as well as those with serious mental health problems who develop dementia.

#### **4.3.11 Cross-cutting issues**

**Recommendation 11:** *Issues that cut across all aspects of dementia care, reflecting the different needs of different groups of people, and that require intervention include:*

- improved access to community, residential and medical services for people with younger onset dementia, including separate strategic planning to meet their specific needs outside the aged care sector;
- improved access for people with dementia and their families and carers who are from culturally and linguistically diverse backgrounds, including improved assessment tools;
- improved access to services for indigenous Australians living with dementia;
- greater public efforts to destigmatise dementia; and

- *smarter use of new information technologies in delivering services, particularly to people in rural and remote areas, including cost-benefit studies of information technology instruments such as web-based information resources and messaging, moderated chats and forums, videoconferencing and clinical communications.*

#### **4.3.12 Health financing**

**Recommendation 12:** *Intergenerational planning needs to acknowledge the need for health, aged and dementia care spending to grow in real and relative terms, with strategies for successfully managing the change. Various tiers of government are already taking steps in this direction. Action-oriented planning, integrally involving stakeholders, needs to address:*

- *appropriate savings or insurance schemes to provide for future health, ageing and dementia needs, including consideration of quarantined increases in the Superannuation Guarantee levy;*
- *consensus on and planning for the future private-public mix of care provision and of insurance provision.*

## METHODOLOGY

### Prevalence

The prevalence estimates are obtained from two data sources, a special data request from the Australian Bureau of Statistics *Survey of Disability Ageing and Carers* together with international meta-analyses from which Professor Anthony Jorm<sup>98</sup> and others have derived previous Australian prevalence estimates. There are weaknesses with both data sets. The ABS data are likely to contain considerable under-statement of prevalence, as it is a household survey (including ‘establishments’) that relies on self-reporting (including by others in the family) and therefore is likely to have downward bias in reporting dementia, particularly in single-person households. It does, however, contain data across all demographic groups and regions with no *a priori* reason why there would be more bias in one group compared to another. Indeed, both 1993 and 1998 data were purchased to confirm the integrity of the demographic splits (see Table 3, Section 1.3.2).

The international (Jorm) data provides a much better estimation of total prevalence, which is quite robust for age cohorts over 60 worldwide. Its limitations are that it does not reflect the gender breakdown and does not comment on prevalence for people under 60. The two data sets were reconciled by applying the demographic splits of the DAC Survey to the overall prevalence estimates of the international data. The estimates for 2002 were thus based on the prevalence rates per 1000 for each demographic cohort projected to the estimated population in each cohort in 2002, as per ABS (2000). The prevalence estimates will be conservative as they will not capture people whose dementia has not been diagnosed.

Projecting prevalence to 2051 (Section 1.3.3) to derive the function in Chart 5 was achieved by applying the prevalence rates for each of the demographic cohorts to the cohorts as projected by the ABS for 2011, 2021, 2031, 2041 and 2051 (Series II, ABS, 2000), fitted with a smoothed curve. Once again the prevalence estimate may be conservative as diagnoses may occur earlier in the future, in line with the current trend.

### Disability and socio-economic impacts

Section 1.4.1 uses the International Classification of Impairments, Disabilities and Handicaps 1980 as a framework to identify whether a person has a disability and the associated level of restriction. People in the 1998 DAC Survey were defined as having a disability if they had one or more of the following impairments that had lasted, or were likely to last, for a period of six months or more:

- loss of sight (not corrected by wearing glasses or contact lenses);
- loss of hearing, that restricted communication or resulted in the use of an aid;
- speech difficulties in preferred language;
- chronic or recurring pain, that restricted everyday activities;
- breathing difficulties, that restricted everyday activities;
- blackouts, fits, or loss of consciousness;
- slowness at learning or understanding;
- incomplete use of arms or fingers;
- difficulty gripping or holding things;
- incomplete use of feet or legs;
- a nervous or emotional condition that restricted everyday activities;
- a restriction in physical activities or in doing physical work;

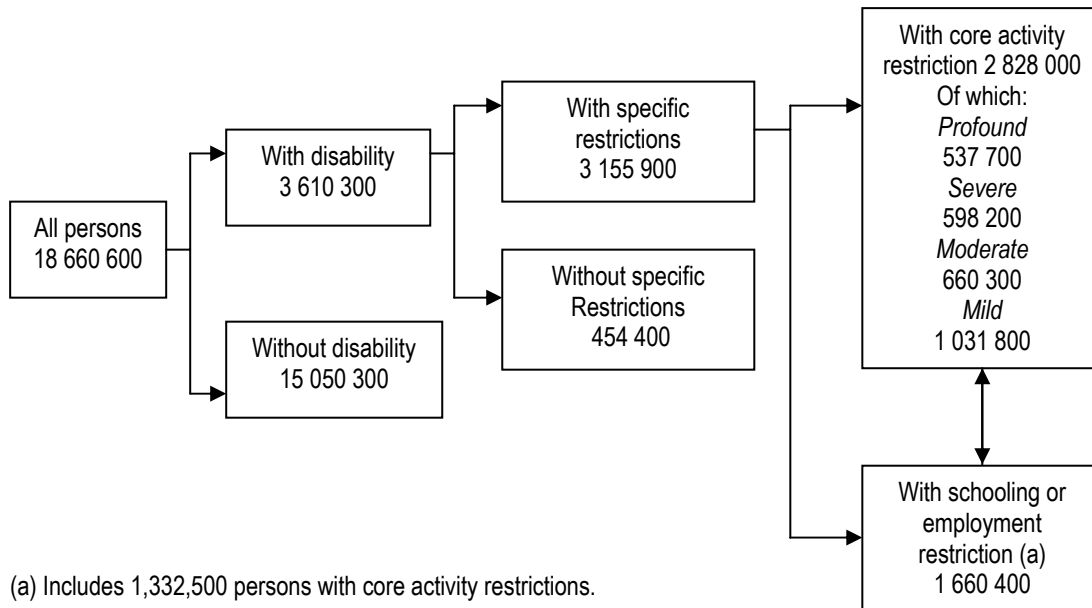
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<sup>98</sup> Director, Centre for Mental Health Research, Australian National University



- a disfigurement or deformity;
- need for help or supervision due to a mental illness;
- long-term effects of head injury, stroke or any other brain damage;
- treatment or medication for another long-term condition or ailment, and still
- restricted in everyday activities;
- any other long-term condition resulting in a restriction in everyday activities.

The flow-chart below shows how the population is subsequently categorised, with 3.61 million Australians in 1998 having a disability, including 98.5% of people with dementia almost all of whom have specific restrictions, and so on as per Table 4.



The ABS included all people who reported having either dementia or Alzheimer's, regardless of other conditions; if someone reported having both conditions, they are only counted once. For the rural-urban comparisons in Table 6, unfortunately data were not available by RRMA group – only the geographic 'section of state' classification. For further descriptions of the ABS methodology see ABS (1999).

**Direct health system costs**

Direct health system costs can be estimated in one of two ways—the 'bottom up' approach, calculated by adding actual (or imputed) costs for a representative cohort of patients, or the 'top-down' approach, which attributes total health expenditures to disease based on available information on the mix of diseases treated and the costs of treatment. While the former is sometimes more accurate in giving up-to-the-minute estimates for specific diseases, there can be problems in obtaining representative samples and representative cost patterns, and the advantage of the latter approach is that there will be consistency of coverage and estimates across diseases, which is more helpful for policy makers.

In this study, the top-down approach is adopted, based on the methodology developed by the Australian Institute of Health and Welfare (AIHW), in collaboration with the National Centre for Health Program Evaluation (NCHPE) for the Disease Costs and Impact Study (DCIS). This major study measures health services utilisation and expenditure for specific diseases and disease groups in Australia, in accordance with the Ninth Revision of the International Classification of Disease (ICD-9) published by the World Health Organisation (WHO). The DCIS methodology has been gradually refined to estimate direct costs of hospitals, GP and specialist medical services, allied professionals, pharmaceuticals, nursing homes,

research and other costs (such as administration), primarily from hospital morbidity data, case mix data and the National Health Survey (NHS), as well as other sources. DCIS methodology is detailed in Mathers et al (1998), while results are provided in Mathers and Penm (1999).

As noted in Section 2.1 (Table 9), the direct health system costs were estimated by the AIHW in 1993-94 as \$714 million. However, this is almost certainly an under-estimate in that only 17 per cent of nursing home costs were attributed to dementia although at least 60% of residents in nursing homes have this condition. The AIHW is currently in the process of reviewing their costings and new estimates are expected in mid-2003. In this paper, the conservative 1993-94 figures were used as a base for projections to 2002. However, the nursing home component was adjusted by a factor of 2.2 to take account of the AIHW's initial substantial under-estimation and to correlate better with expected average costs per resident as provided from other sources. The additional breakdown provided in Table 10 was obtained through a special data request from the AIHW.

Cost projections to 2011 were based on prevalence changes due to demographic ageing (30.2%) together with projected growth in the Health and Community Services GDP deflator. The average growth in this deflator over 1993-94 to 2000-01 was 3.8% per annum. The growth projected in the deflator over 2002 to 2011 was 39.8%, resulting in overall growth of 82%. To this, an adjustment was made to reflect recent large institutional changes, such as the introduction of the three cholinesterase inhibitors on the PBS, as well as highly desirable changes, such as higher levels of research expenditure and spending on primary care (GP education, training and remuneration). The total value of all these factors was only \$69.8m, however – quite small although representing significant growth (an additional 67% over the decade) from a low base for these three items. There are still considerable upside and downside risks – even small percentage changes in the RAC component would change the projection considerably. RAC costs could go down if, for example, pharmacotherapy is effectively administered or could go up if, for example, there are substantial injections to the RAC subsidy or capital costs. Similarly, hospital costs may be lower if waiting times into residential care are reduced, while technological change – always the rogue variable, could either greatly increase or greatly reduce the totals.

### **Home and community care costs**

These were not included in direct costs for historical reasons, although they are very similar in nature. In the 1993-94 AIHW data, nursing homes were part of 'health' expenditures (see Mathers et al, 1999, p6) whereas 'community and public health' programs had only just begun to emerge and were considered more part of 'aged care' expenditure. Today the distinction seems less appropriate but is adhered to on the basis of tradition, and for comparability with most other health spending analyses, which generally do not include home and community care costs.

### **Indirect costs**

The World Health organisation and cost of illness studies in the past have typically classed indirect costs as all those costs that are not direct health system costs, the approach adopted here (except for the special case of home and community care). More recently, there is a trend to separately identify costs that are borne by government as opposed to costs to individuals or society. While this distinction is not made in this paper (except in the scenario modelling) it can be derived from the analysis. However, the economic distinction between real and transfer costs is made, where real costs represent real goods and services whereas transfer costs simply represent money that is transferred from one income unit to another. Transfer costs are interesting in terms of the overall government budget composition. Measurement of indirect costs remains a matter of some debate and controversy.

**Lost earnings and production ('human capital')**: This focuses on the loss of production or earnings associated with illness and premature death. The higher end of such estimates includes absenteeism costs plus the discounted stream of lifetime earnings lost. The lower end might include only the 'friction' period until the worker can be replaced, which would be highly dependent on labour market conditions and un(der)employment levels. The intermediate approach adopted in this paper comprises the lost production of one period due to exit from the workforce and absenteeism. In this case, it is reasonably assumed that, in the absence of illness, people with dementia would participate in the labour force and obtain employment at the same rate as other Australians, and earn the same average weekly earnings (based on ABS Average Weekly Earnings AWE 6302.0 August, released 14 November 2002) of \$696 per week, including full and part time earnings across all occupations and regions. The implicit and realistic economic assumption is that the numbers of such people would not be of sufficient magnitude to substantially influence the overall clearing of the labour market. The estimate of 5% absenteeism for people with dementia is based on costings and data from Access Economics (2002).

**Mortality burden**: The mortality burden makes similar assumptions to those above if, in the absence of the illness, those people with the illness did not die in 2002 but rather were well and participated in the labour force similarly to average Australians, and for the same expected duration. The average age at death of 15-74 year olds with dementia (64.2 years) is derived from the demographic profile of dementia, together with the assumption that an insignificant proportion would work after age 75. The discount rate for the net present value (NPV) of the future income stream – 0.81% – is based on the 30-year average growth of real AWE (with the Consumer Price Index as the deflator) for the period 1981-82 to 2011-12, including forecasts from the Access Economics Macroeconomic Model. A long-term average is required due to the sensitivity of the results to the discount rate. Then:

$$NPV = \sum Y(1+r)^i = \$0.22m \text{ where } Y=\$36,282, r=0.81\% \text{ and } i=0,1,2\dots6$$

The number of people who died (463) is then multiplied by the employment rate (8.5%) to give the number of people (39) who died who would, if they were alive and well, have been employed. Overall,  $39 * \$0.22m = \$8.8m$ , the mortality burden.

Under-estimation derives from the official mortality rate – for over 162,000 Australians with dementia and average life expectancy of 8 years, one would expect *a priori* that the number of deaths would be closer to 20,000 than 5,000 in 2002 as extrapolated from the 1996 AIHW data. However, the conservative approach was adopted and the official estimate used.

**Potential tax revenue foregone**: People with dementia or their families and carers who work less or retire early will not only forego income, but will also pay less personal income tax. The income tax foregone is a product of the average personal income tax rate and the foregone income. With dementia and lower income, there will be less consumption of goods and services, estimated up to the level of the disability pension. Without dementia, it is conservatively assumed that consumption would comprise 90% of income (the savings rate may well be lower than this). The indirect tax foregone is a product of the foregone consumption and the average indirect tax rate. Average tax rates (2002) as shown in Table 13 are derived from the AE macroeconomic model incorporating changes from A New Tax System from 1 July 2000. Tax revenue sacrificed is included as a transfer payment (not a real economic cost).

**Family carer costs**: Placing a value on the cost of unpaid family care is the one of the most difficult aspects of disease costing. It is nonetheless a hugely important indirect cost, and becoming more so as, in Australia, we increasingly accommodate people with disabilities and frail aged people in the community.

There are three potential methods of estimating the cost or value of families and carers:

1. an *opportunity cost* approach – the value of the work (earnings) and/or leisure they sacrifice (possibly also including the health and emotional wellbeing that they sacrifice);
2. the *replacement cost* approach – what the government would have to pay if a family carer were absent;
3. what family carers themselves feel they should be paid (eg, as in the O’shea 2000 Irish study, which interestingly provided an estimate of only £2 to £4 per hour).

There is no data on the latter in Australia. Moreover, a comprehensive “bottom-up” opportunity assessment of carer costs in Australia would also require additional detailed survey work to assess care needs of all levels and types of people with dementia, as well as resolving the contentious issue of valuing lost employment and leisure (particularly when many families and carers are retired). Hence the replacement cost approach has been adopted here, taken as the cost of outsourcing the equivalent care hours at standard remuneration rates for care workers. The calculation using the replacement cost methodology to derive the total carer costs is detailed in section 2.2.2.

**Social welfare payments:** The disability pension, sickness benefits and various allowances paid to those suffering from disease are costs to the tax-paying community, which could be put to alternative use. These are also income transfer payments rather than real economic costs, but again relevant to the public financial position. The Disability Support Pension is the main item here for dementia – this pension was previously known as the invalid pension and was introduced in 1910 as a result of the Invalid and Old-age Pensions Act 1908.

The weighted average payment per week in Table 17 is derived from the Centrelink website ([www.centrelink.gov.au](http://www.centrelink.gov.au)) for each of the various payments, with weights split equally between singles and couples and between the various categories of Rent Assistance. The number of people receiving DSP and pharmaceutical allowance (4,653) is the total number of people with dementia under 65 (6,635) multiplied by the number estimated to be in the lowest two income quintiles (70.2% from Table 5). The people eligible for Rent Assistance is assumed to be only 30% of these (1,396), assuming 70% average home ownership Australia-wide.

**Modifications and aids:** Since these are also not included in the AIHW 1993-94 data, and can be quite substantial, they were included in these costings utilising the Frisch (2001) data, as detailed in Section 2.2.4 and Table 18.

## **Burden of disease**

In recent years, the World Health Organisation (WHO), the World Bank and Harvard University have developed a methodology that provides a comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990 and projected to 2020 (Murray and Lopez, 1996). This approach has been adopted and applied in Australia by the AIHW with a separate comprehensive study in Victoria.

Mathers, Vos and Stevenson (1999) estimate the burden of disease for dementia in 1996 in Annex Tables F, G and H. The YLD, YLL and total DALY elements were then extrapolated to 2002 on the basis of projected growth in the prevalence of dementia over the period. The disability weights used by the AIHW team were 0.270 for mild dementia, 0.630 for moderate dementia and 0.940 for severe dementia.

## BRODATY TRIANGLE

### SEVERITY vs TYPES OF CARE FOR PATIENTS WITH BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA

See Brodaty, Draper and Low (2003).

Tier	Description	Tiers 2-7 percentage and number of the estimated 162,000 people with dementia	Level of Disturbance & Intervention Use Cumulative
1	No dementia	+	Strategies to prevent dementia remain unproven, although some evidence exists for the protective effects of Vitamin E, Vitamin C, statins, antacids, low cholesterol, hormone replacement therapy, education, increased social, mental and physical activities, treatment of vascular risk factors and prevention of hypertension.
2	Dementia no BPSD	39% * <b>63,000</b>	Interventions not widely researched. Medications slowing progression of dementia may also prevent emergence of BPSD. For example galantamine has been shown to lower rate of emergence of BPSD. There is evidence that environmental modifications, higher staff ratios and staff training, may prevent emergence. Early intervention programs for dementia such as Living with Memory Loss program run by the Alzheimer's Associations may also prove effective.
3	Mild BPSD	29% * <b>47,000</b>	Night time disturbance, wandering, mild depression, apathy, repetitive questioning, shadowing. Management through caregiver, staff and general practitioner education, environmental modifications, general activity programs e.g. education of caregivers, multi-sensory stimulation; abilities-focused program; enhanced nursing home environment; education & environmental modifications; client centred care; visual barriers; activities, medication guidelines & educational rounds.
4	Moderate BPSD	21% ♣ <b>34,000</b>	Major depression, verbal aggression, psychosis, sexual disinhibition, wandering. Management through psychogeriatric consultation – medications, behavioural management, e.g. physical activity programme; individualised Music; stimulated presence; behavioural management techniques; bright light therapy; outdoor environments; increased environmental quality; Alzheimer's Australia South Australia's hotline for BPSD.
5	Severe BPSD	10% ♣ <b>16,000</b>	Severe depression, psychosis, screaming, severe agitation. Management in dementia specific nursing homes or by psychogeriatric team e.g. dementia special care units; individually tailored psychogeriatric management.
6	Very severe BPSD	0.9% ♣ <b>1,500</b>	Physically aggressive, severely depressed, suicidal. Management in psychogeriatric or neurobehavioural units e.g. CADE units; psychiatric hospitalisation.
7	Extreme BPSD	0.1% ♣ <b>200</b>	Physically violent. Management in Intensive Specialist Care Unit.

Please note Tiers 2-7 only included in the estimated 162,000 people with dementia in Australia in 2002

+ In 2002 there are approximately 2.5 million people aged 65 years and over in Australia and some 162,000 of them have some form of dementia. People with dementia represent 6.6 percent of this population.

\*Statistics based on clinical observations

♣ Statistics based on Lyketsos et al (2000).

## **GLOSSARY OF COMMON ABBREVIATIONS**

A $\beta$	beta-amyloid
ABS	Australian Bureau of Statistics
ACAT	Aged Care Assessment Team (in Victoria: ACAS – Aged Care Assessment Service)
AD	Alzheimer’s Disease
ADAS-Cog	Alzheimer’s Disease Assessment Scale – cognitive subscale
ADL	activities of daily living
AIHW	Australian Institute of Health and Welfare
ALOS	average length of stay
APP	amyloid precursor protein
BPSD	Behavioural and Psychological (Signs and) Symptoms of Dementia
CACP	Community Aged Care Packages
CDAMs	Cognitive Dementia and memory Services
CEI	cholinesterase inhibitor
CEWT	Carer Education and Workforce Training (project)
COPs	Community Options Projects
CPI	Clinical Practice Improvement (study) or Consumer Price Index (context-dependent)
CT	computed tomography
DAC	(ABS Survey of) Disability Ageing and Carers
DALY	disability adjusted life year
DESP	Dementia Education Support Program
DHA	Department of Health and Ageing
DLB	dementia with Lewy bodies
DSM-IV	diagnostic and statistical manual – version four
EACH	Extended Aged Care in the Home
EPC	Enhanced Primary Care
ESDSRP	Early Stage Dementia Support and Respite Program
ESP	extra service provider
EU	European Union
FTD	fronto-temporal (lobe) dementia
FY	fiscal (financial) year (1 July to 30 June)
GDP	gross domestic product
GP	general practitioner
GPCOG	General Practitioner Assessment of Cognition
HACC	Home and Community Care (program)
ICD-10	International Classification of Diseases – tenth revision
IT	information technology
MCI	mild cognitive impairment
MMSE	mini-mental state examination
MRI	magnetic resonance imaging



NAPDC	National Action Plan for Dementia Care
NDBAS	National Dementia Behaviour Advisory Service
NGF	nerve growth factor
NHS	National Health Survey
NRCP	National Respite for Carers Program
NRDTI	National Residential Dementia Training Initiative
NSAID	non-steroidal anti-inflammatory drug
PCAI	Personal Care Assessment Instrument (pre-1997)
PET	positron emission tomography
PGU	psycho-geriatric (care) units
PHI	private health insurance
RAC	residential aged care
RCI	Resident Classification Instrument (pre-1997)
RCS	Resident Classification Scale
TGA	Therapeutic Goods Administration
UK	United Kingdom
US	United States of America
VaD	vascular dementia
YLD	years of healthy life lost due to disability
YLL	years of life lost due to premature death

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