

THE DEMENTIA EPIDEMIC: ECONOMIC IMPACT AND POSITIVE SOLUTIONS FOR AUSTRALIA

Chapter 3 - Comparisons, Constraints and Scenarios

Prepared for
ALZHEIMER'S AUSTRALIA
by



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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

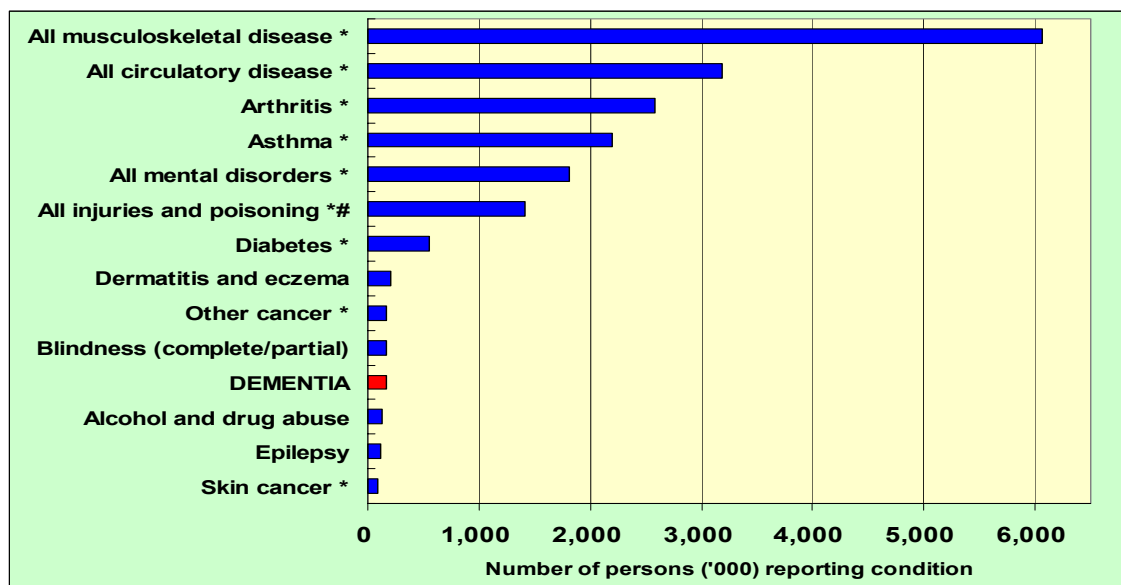
Dementia is more common than epilepsy or skin cancer.

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)⁷⁹. 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
Mental*	2,586	1,007	432	198	83	718	147
<i>of which dementia</i>	714	110	11	2	4	539	48
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
Total	31,397	14,062	5,640	4,042	3,075	2,647	1,932
Dementia as % of total	2.3%	0.8%	0.2%	0.1%	0.1%	20.4%	2.5%

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.

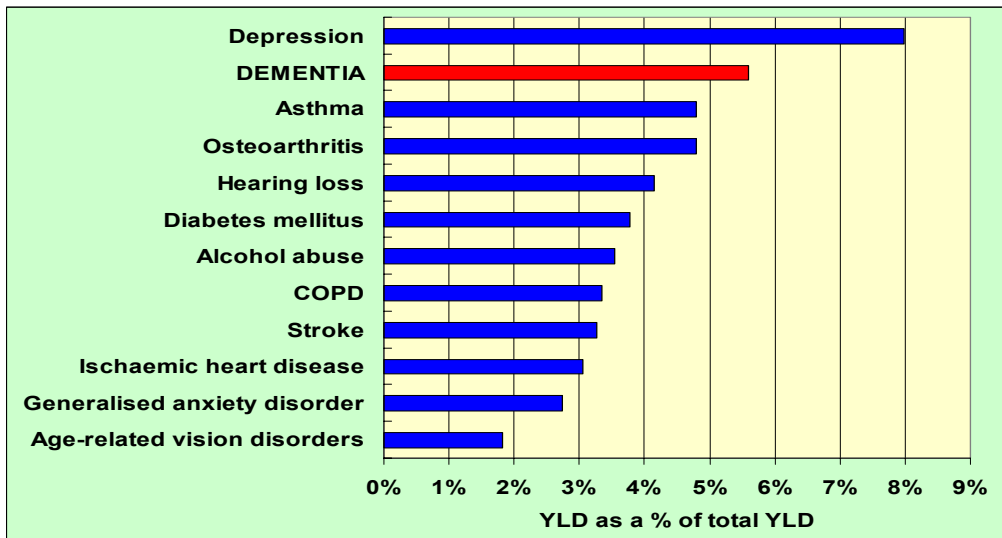
⁷⁹ Although this data relates to the year 1993-94, it is the most recent available. Updated cost data are expected from the AIHW in June 2003.

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	Dementia	8.9
4	COPD	5.8	4	COPD	4.0
5	Dementia	5.3	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 2000⁸⁰ – 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.⁸¹

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.

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

⁸¹ 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.⁸² 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).

⁸² 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 lists⁸³ 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.⁸⁴ This has led to greater demand for dementia-specific care facilities, although policy remains to

⁸³ 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).

⁸⁴ 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 Grants⁸⁵, 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;

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

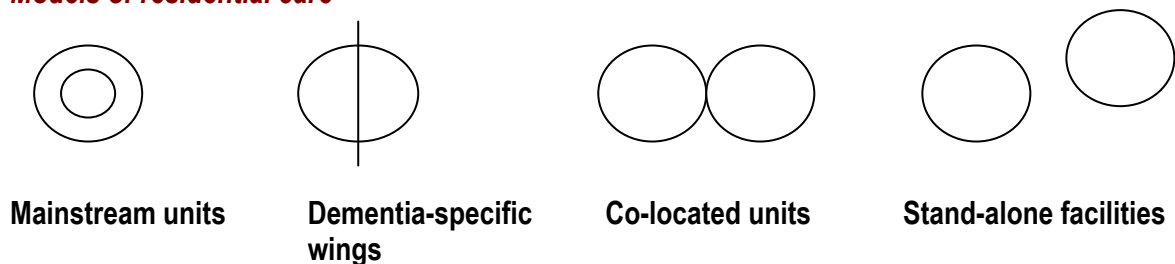
- review of remuneration for nursing and personal care staff;
- planning ratios need to make provision for dementia care and challenging BPSD;
- descriptors in the RCS should concord with ACAT assessments; ‘high care’ should include the need for behaviour management and environment, not just the need 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.

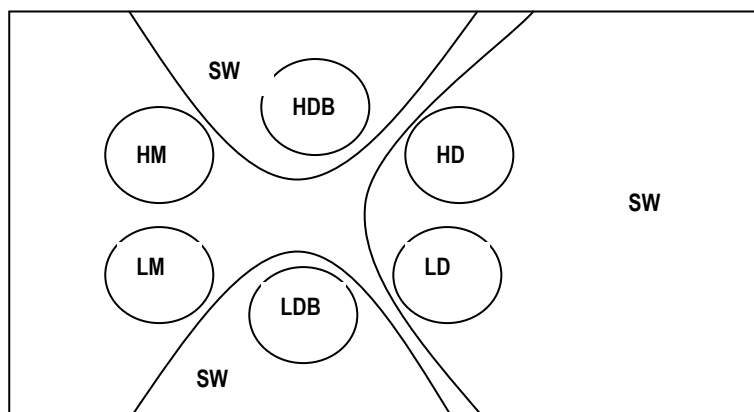
Rosewarne et al (2000) proposes the ‘**Cluster house campus model**’ – separate buildings (‘houses’) each with around 15 beds within a single complex (‘campus’) of around 90 beds. The houses would operate largely as independent care units with a caregiver supported by an on-staff visiting registered 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, '**21st 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.

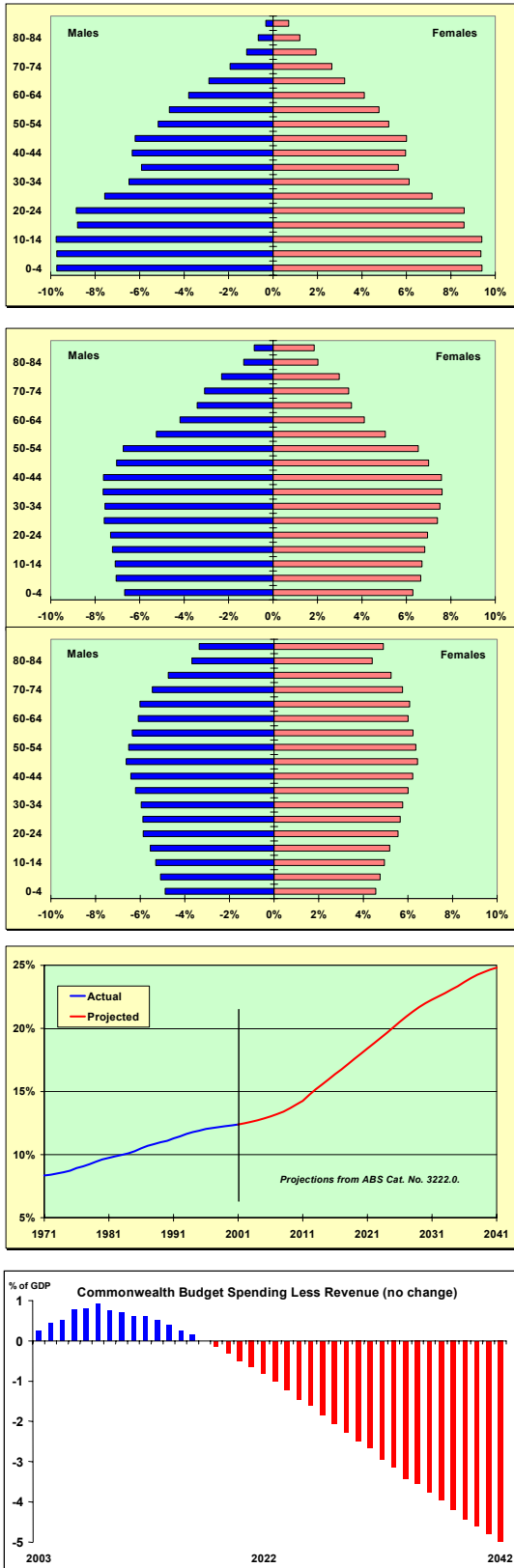
After her 81st birthday, Rose's wandering develops into agitated walking, she loses many language skills, and her GP and specialist describe her dementia as 'moderate' and her behaviours as 'B1'. She strides for some hours each day in the beautiful adjacent secure walking area, Serene Way. She also enjoys 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	2003-04	2004-05	2005-06	Total
	\$m	\$m	\$m	\$m	\$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.⁸⁶ 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)

⁸⁶ See 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;⁸⁷
- (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.

⁸⁷ 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.⁸⁸

⁸⁸ 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 ²	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.”

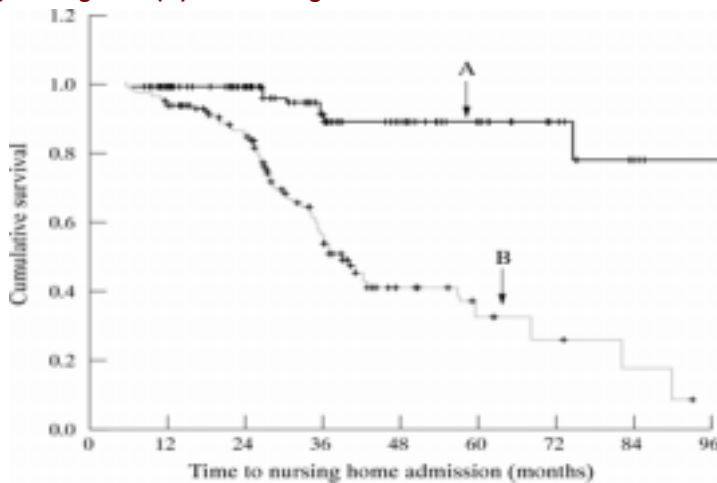
An implication for Australia is that the six-month review period required by the PBS for access to subsidised CEIs is too short. Furthermore:

“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.⁸⁹

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)	
Residential						
Residential care	36,547	77,902	2,847.1	58,427	2,135.3	712
Community						
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
Net difference						(\$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		Total		276

* 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.

⁸⁹ 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)	
RESIDENTIAL						
Residential care	36,547	77,902	2,847.1	58,427	2,135.3	712
Community						
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
Net difference						(\$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		Total		959

* 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
Return to \$1 p.a.	\$7.27

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 appears⁹⁰. 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.

⁹⁰ 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.