THE DEMENTIA EPIDEMIC: ECONOMIC IMPACT AND POSITIVE SOLUTIONS FOR AUSTRALIA

Chapter 2 - The Dementia Burden for Australian People

Prepared for
ALZHEIMER'S AUSTRALIA
by

Canberra
March 2003

This report was prepared by Access Economics for Alzheimer's Australia, funded by an unrestricted grant from Janssen-Cilag and Pfizer who had no part in the direction or findings contained in this report.

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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
Dementia	***110***	***11***	***2***	***9***	***582***	***714***	***23.6%***
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%
Total	*941*	*438*	*199*	*334*	*1110*	*3022*	100.0%

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.

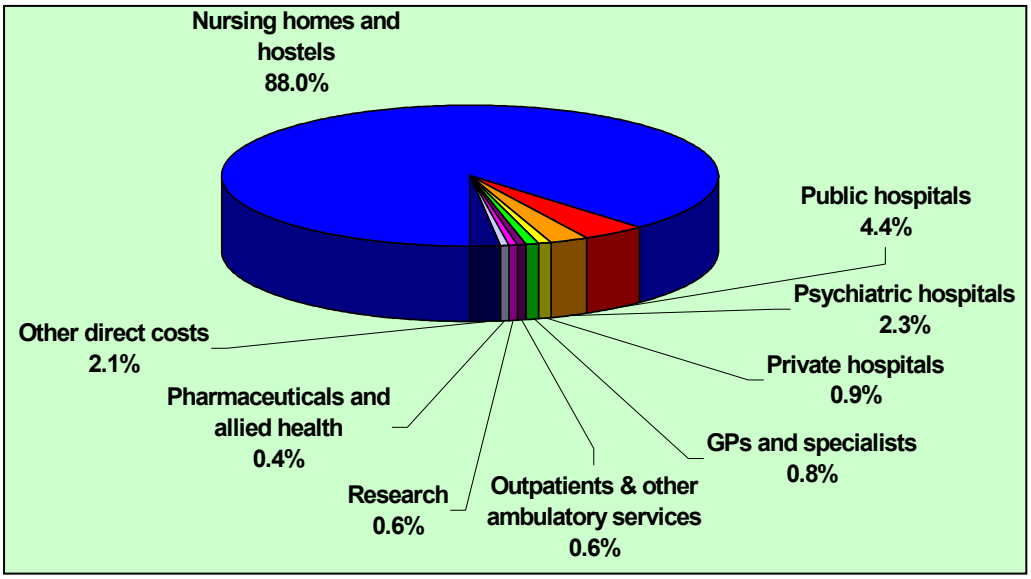
Table 10: Components of direct health costs for dementia, 2002

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%
Total direct	3,235.9	100.0%

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[74]. 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.

[74] 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

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

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.

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%
Total direct	$5,959.7	100.0%

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[75] – plus spending on other dementia-specific programs (such as funding for Alzheimer's Australia) which is estimated as $40m in 2002.[76] 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.

[75] The total HACC program, including State and Territory spending, amounts to $1.1 billion.
[76] 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

	$m	per person at home	per person receiving services	% of total DHA
Home-based Aged Care	$175	$2,071	$2,554	16%
	$m	**per person in place**	**DHA av. cost per occupied place**	**% of total DHA**
Residential Aged Care	$2,847	$36,547	$28,796	66%
	$m	**per person with dementia**	**per person receiving services**	**% of total DHA**
Total	$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

Potential Earnings Lost	**$355.3 million**
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
Total potential tax revenue lost	**$99.7 million**

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

	Males	**Females**	**Persons**
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
Total deaths	***1,716***	***3,411***	***5,127***

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

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.

"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
Total	*84,394*		*89.0*	*1,713.2*

Source: Access Economics estimates.

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

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.

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

		No. of people with dementia at home		
	Value of transfer payment	Before means test	After means test and wastage ie, receiving payment	Value of payments, $m
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
Total		*84,394*	*44,394*	*324.4*

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

	weekly payment	receiving benefit	total cost $m
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
Total			*52.0*

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 Continence 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
Total	$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).[77]

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

[77] As quoted in DHA (2002a) Attachment C.

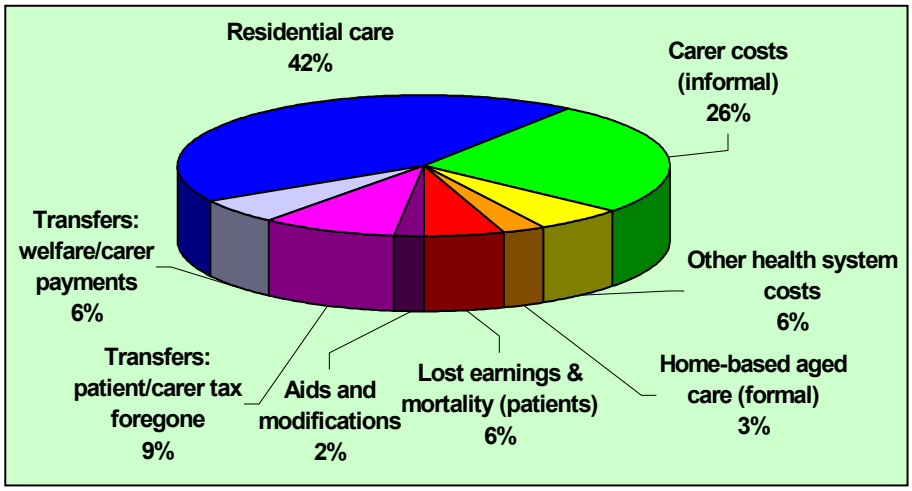
In per capita terms, the indirect financial costs of ageing are approaching $20,000 per person with dementia p.a., while the direct health and ageing costs of dementia are over $20,000 per person p.a., including home and community care of just over $1,000 per person with dementia in 2002 (but $2,554 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[78]. Direct costs alone will reach 1.6% of GDP.

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

$ million	**Real cost**	**Transfer payments**	**Total**	**Per person with dementia**	**% GDP 2002**	**%GDP 2051**
Direct health costs	*$3,235.9*		*$3,235.9*	$19,938	0.45%	1.6%
Including residential care	$2,847.1		$2,847.1	$17,542*		
Home and community care	$174.8		$174.8	$1,077*		
Indirect financial costs						
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%	1.0%
Tax foregone (carers)		$489.7	$489.7			
Welfare payments		$52.0	$52.0			
Aids & modifications	$119.8		$119.8			
Subtotal indirect financial costs	*$2,197.2*	*$968.3*	*$3,165.4*	$19,504	0.44%	1.6%
Total financial costs	**$5,607.9**	**$968.3**	**$6,576.1**	$40,519	0.91%	3.3%

*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

[78] 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

	DALYs	YLL	YLD
Males	***44,039***	***10,812***	***33,227***
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
Females	***73,043***	***20,620***	***52,424***
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
Total	***117,083***	***31,432***	***85,651***
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.