

DEMENTIA IN THE ASIA PACIFIC REGION: THE EPIDEMIC IS HERE

REPORT BY
ACCESS ECONOMICS PTY LIMITED

FOR

**ASIA PACIFIC MEMBERS OF
ALZHEIMER'S DISEASE INTERNATIONAL**

21 SEPTEMBER 2006



**ACCESS
ECONOMICS**



FOREWORD

The 15 Asia Pacific member organisations of Alzheimer's Disease International (ADI) agreed at their meeting in Singapore in May 2005 to commission a report that would draw the attention of governments, international organisations and aid agencies to the dementia epidemic and the threat that it posed to public health systems. We were asked to act as an Executive to oversee the project.

It is evident that dementia already has dramatic effects on the lives of millions of people across the region and on public health costs. There is no cure yet but much can be done to improve the quality of life of people with dementia and the families who care for them.

The key is to recognise dementia as a health priority and, in doing so, to plan the action to be taken. The Kyoto Declaration by ADI provides a framework for determining the actions required. Actions need to be sensitive to the needs of individual countries respecting their cultural, social and economic contexts.

It is also important to promote collaboration within the region. Countries have a great deal to share with one another in the development of effective health and care services for people with dementia and their families. One priority is to undertake research which improves the information base for those planning services.

It is a remarkable step forward for Alzheimer's organisations in the region to agree to this report and its release as a shared basis for advocacy. We sincerely hope that the report will be useful to policy makers at both the national and international levels.

We would like to thank the Tsao Foundation and ADI for funding this report. We would like to thank Access Economics for the professionalism with which they have put the report together.

Glenn Rees
National Executive Director
Alzheimer's Australia

Dr Ang Peng Chye
President
Alzheimer's Singapore

Mrs Sung-Hee Lee
President
Alzheimer's South Korea





TABLE OF CONTENTS

FOREWORD	i
EXECUTIVE SUMMARY	iv
1. WHAT IS DEMENTIA?	1
1.1 Types of dementia.....	1
1.2 Risk factors for dementia	1
1.3 Disease burden	3
1.3.1 Burden of disease in the Asia Pacific region in 2002.....	3
1.3.2 WHO projections of regional burden of disease from dementia	6
2. PREVALENCE NOW AND TOMORROW	9
2.1 Prevalence studies	9
2.1.1 Early estimates of prevalence rates by age group	9
2.1.2 Regional differences in studies	9
2.1.3 Recent world prevalence studies	10
2.2 Regional prevalence and incidence estimates.....	12
2.2.1 Prevalence and incidence rates used in this study	12
2.2.2 United Nations demographic data	13
2.2.3 Results – 2005 to 2050	13
3. ECONOMIC AND SOCIAL IMPACTS	16
3.1 Health care services.....	16
3.2 Informal family care	17
3.3 Community care	18
3.4 Residential care	18
3.5 Costs	19
4. COST EFFECTIVE INTERVENTIONS	22
4.1 The importance of economic analysis and cost-effectiveness studies	22
4.2 Cost effectiveness of pharmacological and non-pharmacological interventions	23
5. POLICY CHALLENGES AND FRAMEWORKS	25
5.1 2004 Consensus Statement.....	25
5.2 Pathway of dementia.....	25
5.2.1 Pre-dementia	26
5.2.2 Early dementia.....	26
5.2.3 Moderate dementia.....	27
5.2.4 Severe dementia	27
5.2.5 End-of-life issues	27
5.3 The Kyoto declaration	28
5.4 ADI call to action 2005	30
5.5 Research	30
6. CONCLUSIONS AND RECOMMENDATIONS	32
REFERENCES	33
APPENDIX: BRODATY TRIANGLE	39

FIGURES

Figure 1-1: Burden of disease, major groups by gender, WPRO & SEARO, 2002, million DALYs	5
Figure 1-2: Burden of disease, dementia comparators, by gender, WPRO & SEARO, 2002, million DALYs	5
Figure 1-3: Burden of disease, dementia by age, WPRO & SEARO, 2002, DALYs	6
Figure 1-4: Burden of disease, WPRO & SEARO, by group, 2005-30, % total DALYs	7
Figure 1-5: Burden of disease, dementia, by gender, WPRO & SEARO, 2005-30, '000 DALYs	8
Figure 2-1: Dementia prevalence, WPRO & SEARO, 2001, 2020, 2040	12
Figure 2-2: Total Prevalence, China, India and other regional, 2005-50	14
Figure 2-3: Total Incidence, China, India and other regional, 2005-50	14

TABLES

Table 1-1: Projected life expectancies at birth and at age 60, by gender and region, 2002-30, years	7
Table 1-2: Burden of disease, dementia, by gender, WPRO & SEARO, 2005-30, '000 DALYs	8
Table 2-1: Dementia prevalence 2001, 2020, 2040 by WHO region	11
Table 2-2: Dementia prevalence rates, by age group, WPRO and SEARO, %	11
Table 2-3: Prevalence and incidence rates, by age and gender, this study, %	13
Table 2-4: Prevalence and incidence, Asia Pacific region, 2005-50, summary	15
Table 2-5: Prevalence and incidence, ADI Asia Pacific region and non-ADI Asia Pacific region	15
Table 5-1: Minimum actions required for the care of people with dementia	28





EXECUTIVE SUMMARY

The 15 Asia Pacific member organisations of Alzheimer's Disease International (ADI) agreed at their meeting in Singapore in May 2005 to commission a report that would draw the attention of governments, international organisations and aid agencies to the dementia epidemic and the threat that it posed to public health systems.

All Alzheimer's organisations in the region have agreed to the content of this report and its release as a shared basis for advocacy.

The report:

- looks at aspects of the dementia epidemic in the Asia Pacific region;
- describes dementia and the identified risk factors for dementia;
- considers current burden of disease data and future projections;
- provides estimates/projections of dementia prevalence/incidence by country;
- considers economic and social impacts of dementia;
- describes cost-effective interventions and available policy frameworks; and
- makes recommendations for action.

The analysis draws on developed world data in the absence of accessible Asia Pacific data.

The report was funded by the Tsao Foundation and ADI.

The facts

The 15 ADI Asia Pacific member organisations are located in Australia, China, TADA Chinese Taipei, Hong Kong SAR, India, Indonesia, Japan, Malaysia, New Zealand, Pakistan, Philippines, Singapore, South Korea, Sri Lanka and Thailand.

Other countries included in this analysis are Bangladesh, Bhutan, Brunei Darussalam, Cambodia, Macao, the Democratic People's Republic of Korea, East Timor (Timor Leste), Laos, Myanmar, Nepal, Papua New Guinea and Vietnam.

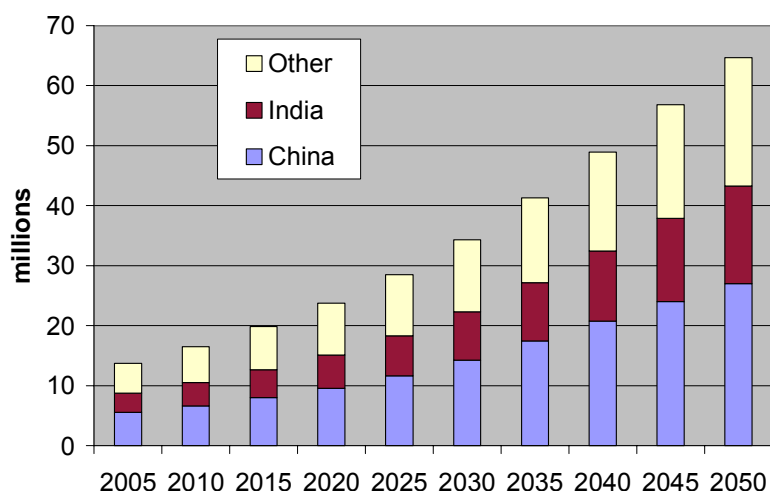
The total population of the region in 2005 is estimated from United Nations data as 3.58 billion. The population over 65 years is estimated as 238.9 million with 37.2 million people aged over 80 years. There is great diversity in terms of economies, language and religion.

The dementias are a group of diseases characterised by loss of short-term memory, other thinking (cognitive) abilities and daily functioning. Alzheimer's disease and vascular dementia are the commonest types of dementia.

The number of those with dementia will increase in the Asia Pacific region from 13.7 million people in 2005 to 64.6 million by 2050.



TOTAL PREVALENCE: CHINA, INDIA AND OTHER REGIONAL, 2005-50



The number of new cases of dementia in the region is projected to increase from 4.3 million new cases per year in 2005 to 19.7 million new cases by 2050.

PREVALENCE AND INCIDENCE, ADI ASIA PACIFIC AND NON-ADI ASIA PACIFIC

	2005		2020		2050	
'000 people	Prevalence	Incidence	Prevalence	Incidence	Prevalence	Incidence
Australia	195.4	60.2	301.3	91.1	664.1	199.7
China (inc Macao)	5,541.2	1,721.0	9,596.3	2,916.7	27,004.4	8,269.0
Hong Kong SAR	59.7	18.5	109.2	32.6	332.0	99.6
India	3,248.5	1,026.8	5,541.8	1,714.4	16,290.1	4,974.6
Indonesia	606.1	191.4	1,016.8	314.1	3,042.0	932.0
Japan	1,871.2	570.2	3,251.3	983.4	4,873.1	1,417.7
Malaysia	63.0	20.1	126.8	39.0	453.9	138.8
New Zealand	38.2	11.8	54.6	16.6	117.6	35.5
Pakistan	330.1	107.3	566.6	179.3	1,916.2	584.3
Philippines	169.8	54.8	316.3	99.2	1,158.9	353.9
Singapore	22.0	6.8	52.6	15.7	186.9	56.7
South Korea	246.3	75.5	542.2	164.3	1,569.9	475.4
Sri Lanka	86.0	26.9	148.0	45.1	409.0	125.0
TADA Chinese Taipei	138.0	43.1	253.4	76.6	659.3	199.4
Thailand	229.1	71.4	450.2	137.2	1,233.2	377.0
ADI Asia Pacific	12,844.3	4,005.9	22,327.6	6,825.2	59,910.6	18,238.7
Non-ADI Asia Pacific	859.3	276.2	1,399.6	437.1	4,730.9	1,448.6
Total region	13,703.6	4,282.1	23,727.1	7,262.3	64,641.5	19,687.3

Different studies give slightly different results depending on their methodology. But the dementia epidemic is a certainty because the numbers of people with dementia increase with an ageing population. And those aged over 60 in the Asia Pacific will increase from under 10% today to 25% of the total population by 2050 and those over 80 years from 1% to 5% of the population.



Apart from the increase in numbers of people with dementia there are other factors that will exacerbate the social and economic impact of dementia. These include urbanisation, trends away from extended families and towards nuclear families, and the increasing number of elderly people who thus live alone. The ability to care for these people will depend on a mix of formal and informal care giving. Many countries in the Asia Pacific region may not be well prepared to provide quality health and care services for people with dementia and their family care givers.

Dementia has the potential to have a devastating impact on the public health systems of Asia Pacific countries. This is not only because of the “greying” of the population but because dementia is among the most disabling of all chronic diseases. The “burden of disease” is measured by the number of years of healthy life lost as a consequence of a condition. It is the sum of the “mortality burden” (the years of life lost due to premature death) and the “disability burden” (the years of healthy life lost due to disability). Based on World Health Organization data there is evidence to suggest that:

- ❑ Neuropsychiatric conditions are second only in disability burden to infectious and parasitic diseases.
- ❑ The disease burden of dementia exceeds that of malaria, tetanus, breast cancer, drug abuse or war and:
- ❑ The disease burden from dementia is projected to increase by over 76% over the next quarter century.

How this translates in terms of costs in public health will vary greatly depending on the country and what mix of care is provided, although costs will rise relative to gross domestic product as prevalence increases. The most effective way to make savings would be if the onset of dementia could be delayed or incidence reduced through prevention approaches arising from new research.

For the 15 Asia Pacific region ADI members, Wimo et al (2006b) have estimated the cost of dementia as \$60.4 billion (in 2003 US dollars). 70% of the total regional costs of dementia care were estimated to be in the advanced economies, which contain 18% of the prevalence.

The Challenge

There are major challenges for the World Health Organization and governments in the Asia Pacific to change:

- ❑ Limited awareness of dementia and in many countries a cultural context that denies its existence or attaches stigma to the condition.
- ❑ An assumption that dementia is a natural part of ageing and not a result of disease.
- ❑ Inadequate human and financial resources to meet care needs and limited policy on dementia care.
- ❑ High rates of institutionalisation in cities in some countries and lack of facilities in other regions.
- ❑ Inadequate training for professional care givers and a lack of support for family care givers.



There is much sound advice about how to meet these challenges. The tragedy for people with dementia and their family and care givers in the Asia Pacific will be if this advice is not put into practice.

First, there is now a good understanding of the pathway of dementia from early difficulties resulting from subtle changes in memory and behaviour to high dependence on care and incapacity. Whilst this pathway will vary from individual to individual, it is relentless in the loss of individual autonomy. The required service responses will vary at different points in the pathway and with the individual's needs.

Secondly, an action plan for dementia based on the "minimum actions required for the care of people with dementia" was presented at the 20th International Conference of Alzheimer's Disease International in 2004 in Japan - the Kyoto Declaration (see below).

Thirdly, a growing body of evidence demonstrates the cost effectiveness of various pharmacotherapies and the benefits from early diagnosis, early intervention and family care giver education, training and support.

Recommendations

The Asia Pacific region countries already have over half of the world's population. Throughout this region, numbers of people with dementia will at least triple between now and 2050.

Well formulated and planned government policies, in collaboration with private and community organisations, can reduce the cost impacts of the projected prevalence growth through cost-effective interventions that deliver quality outcomes for people with dementia and their families.

Governments in the Asia Pacific region will assist people with dementia and their family care givers if they recognise that:

- Dementia is a health priority.
- Cost-effective interventions exist.
- Policy frameworks and plans support all sectors in making a difference for people with dementia and their families.

The 2004 Kyoto Declaration (attached) provides a practical way forward and the framework for a program of action for Governments, non-government organisations and other stakeholders. Some Governments have already announced national policies.

It is recommended that all Asia Pacific Governments:

- 1 Consider and adopt the Kyoto Declaration, in the light of their own demographic, cultural and health care contexts.
- 2 Develop individually tailored national strategies for dementia that:
 - Create the climate for change through greater awareness and destigmatisation of dementia.
 - Build effective constituencies and coalitions for partnership between policy makers, clinicians, researchers, care givers and people with dementia.
 - Promote the development of primary and community care services that are responsive to the needs of people with dementia and their family care givers.



- ❑ Provide information on the adoption of lifestyles that may reduce the risk of dementia.
 - ❑ Make provision for special needs, including people with younger onset dementia, and people with behavioural and psychological symptoms of dementia (BPSD).
- 3 Promote investment in research for cause, prevention and quality dementia care.

The issue of dementia is significant enough to justify collaborative action between regional governments. This could take the form of an initial meeting of Ministers or policy makers to set a joint agenda or collaboration, for example, in the areas of research and service delivery.

Access Economics
21 September 2006





1. WHAT IS DEMENTIA?

Dementia is a progressive, degenerative condition that affects memory, thinking, behaviour, emotion and day-to-day functioning.

1.1 TYPES OF DEMENTIA

There are numerous diseases that cause dementia. Some of the most common are described below.

Alzheimer's disease is the most common cause of dementia and accounts for 50-60% of all cases. It is caused by abnormal brain tissue changes – known as 'plaques and tangles' that were identified by Alois Alzheimer, a German psychiatrist and pathologist, in 1906. Onset of AD is insidious and the disease lasts for 3-20 years from diagnosis, which is largely related to age.

Vascular dementia accounts for a further 20-30% of cases of dementia, and results from a narrowing of the arteries supplying blood to the brain. The lack of blood can cause damage to the brain, either due to reduced oxygen supply, strokes or mini-strokes, demyelination or mixed effects. Onset and life expectancy is similar to that of Alzheimer's disease, although the disease course can be highly variable.

Dementia with Lewy bodies (or Lewy body dementia) comprises about 10% (or more) of all cases of dementia. Lewy bodies, the hallmark of this type of dementia, are seen under the microscope as abnormal inclusions in brain cells. Progress is quite rapid, and there can be parkinsonian symptoms, hallucinations, falls and fluctuations in consciousness.

Fronto-temporal (lobe) dementia was described by Arnold Pick ('Pick's disease'). As well as tangles, there are rounded proteins found in brain cells called 'Pick bodies'. Its onset is earlier (sometimes as young as 30-40 years) and family history is an important risk factor. Several variants of fronto-temporal dementia exist featuring personality and behavioural changes and speech difficulties.

Younger onset dementia refers to onset of dementia in people aged under 65. Younger people with dementia are more likely to be working; have children at home; have heavier financial commitments; have a heritable form of dementia; have high levels of psychological and behavioural symptoms; have difficulty receiving care; have family care givers with higher levels of distress; and have higher associated costs and burden overall.

1.2 RISK FACTORS FOR DEMENTIA

While the causes (aetiology) of dementia are not always completely understood, certain risk factors are known.

Age is the most well-accepted risk factor, with the likelihood of dementia increasing from around 1 in a 1000 for people under 65, to 1% for people in their sixties to nearly 25% for people 85 years and over.

Family history: Genetic factors contribute to dementia risk. Younger onset familial Alzheimer's disease is a relatively rare autosomal dominant condition, i.e. inherited by



50% of each generation. Abnormal genes have been identified on chromosomes 14, 21 and 1. Other genes have also been associated with a greater risk of Alzheimer's disease but do not necessarily cause the disease. The most important of these genes is Apolipoprotein E (ApoE). The ApoE e4 variant increases the risk of developing Alzheimer's disease but does not cause it. There are strong familial indicators for fronto-temporal dementia: in some cases there is a mutation of a gene on chromosome 17 that makes tau, inhibiting the protein's function and causing it to form tangles. Further research is required to understand the interaction of genes and environment in the causes of the dementias. There is growing concern that genetic testing may lead to misunderstanding, such as insurance companies or employers misusing positive test results.

Gender: Over the age of 80, women are at slightly higher risk of Alzheimer's disease, while men may be at higher risk of vascular dementia. The Boston University School of Medicine Multi-Institutional Research in Alzheimer's Genetic Epidemiology study showed that by age 93, female risk is 13% higher than male risk.

Cardiovascular risk factors, stroke-related and atherogenic causes contribute to vascular dementia and there is increasing evidence that they also contribute to Alzheimer's disease. These include high blood pressure (severe systolic hypertension), narrowing of the arteries (atherosclerosis), irregular heartbeat (atrial fibrillation), ischaemic (coronary) heart disease and attacks (myocardial infarction), diabetes, high saturated fat and LDL cholesterol intake and smoking. Coronary artery bypass graft surgery may contribute to vascular dementia.

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

Other possible risk factors include depression, diabetes, high levels of homocysteine (an amino acid) in blood, previous thyroid diseases, head trauma (eg, from motor vehicle accidents or boxing) and excessive alcohol intake. There has been some evidence of lower prevalence rates for Alzheimer's disease in some developing countries and in rural areas, although the evidence regarding ethnic and cultural influences is unclear.

Possible protective factors that may reduce the risk of developing Alzheimer's disease include:

- ❑ **Use of pharmacotherapies:** Epidemiological, though not treatment study, research has demonstrated that the use of *anti-inflammatory drugs* (eg, in treating arthritis) – including *non-steroidal anti-inflammatory drugs* (NSAIDs) – and *statins*, the most widely used cholesterol-lowering drugs, may reduce Alzheimer's disease risk or delay its onset. *Oestrogen* was thought to have a protective effect until the Women's Health Initiative Memory Study, a large US trial, demonstrated an increased risk of Alzheimer's disease in women aged 65 or more taking hormone replacement therapy compared to those on placebo.
- ❑ **Diet:** High intakes of antioxidants from food – vitamin E and vitamin C for example — may guard against Alzheimer's disease Other studies have identified



fish, wine and Ginkgo biloba consumption as having a potentially protective effect.¹ Theoretically, consumption of more folic acid and vitamins B6 and B12, which can reduce homocysteine levels, may also guard against Alzheimer's disease.

1.3 DISEASE BURDEN

Mortality: The dementia specific mortality rate is twice the rate of people without dementia, controlling for co-morbidities and socio-demographic factors. 70% of people over 75 with dementia die within five years (Wimo et al, 1998:24). Death certificates grossly under-report dementia as the cause of death, often citing instead respiratory infection. Life Extension Foundation (2002) estimates Alzheimer's disease to be the fourth leading cause of death in developed nations (after heart disease, cancer and stroke).

Morbidity: Morbid effects of dementia can include, depending on type: gradual memory loss; decline in ability to perform routine tasks; disorientation to time and place; impaired judgement, abstract thinking and physical coordination; difficulty in learning and concentration; loss of language and communication skills; changes in personality, behaviour and mood (many with Alzheimer's have depressive symptoms and about 20% exhibit aggression, more commonly in men); hallucinations (experienced by 16% of people with Alzheimer's) and delusions (false beliefs), often paranoid (30% of people with Alzheimer's); loss of initiative; altered sleep patterns, eating disturbances and screaming. Cummings (2001) lists the prevalence of neuropsychiatric symptoms that commonly accompany Alzheimer's disease as agitation (60% to 70% of people), apathy (60% to 70%), depression (50%), anxiety (50%), irritability (50%), delusional disorders and psychosis (40% to 50%), disinhibition (30%) and hallucinations (10%). The symptoms and behaviours of dementia, as well as the decreased functionality in activities of daily living (ADL), can be physically and emotionally difficult for families and care givers to manage, creating additional loss of wellbeing.

1.3.1 BURDEN OF DISEASE IN THE ASIA PACIFIC REGION IN 2002

"Burden of disease" is a concept relating to loss of health, life and wellbeing that originated in work by the Harvard School of Public Health in collaboration with the World Bank and World Health Organization (Murray and Lopez, 1996). As well as generating a comprehensive and consistent set of estimates of mortality and morbidity by age, sex and world region for the year 1990, the original global burden of disease study also introduced a new metric – the disability adjusted life year (DALY) – to quantify the burden of disease.

¹ For example, *British Medical Journal* (fish), October 2002, the UK Alzheimer's Society (ginkgo), October 2002, and *Journal of Neurology* (wine) November 2002 articles cited in Alzheimer Europe (2002).



Disability-adjusted life years: One DALY represents the loss of one year of equivalent full health. DALYs for a disease are the sum of the years of life lost due to premature mortality in the population and the years of healthy life lost due to disability.

WHO has since undertaken more recent assessments of global burden of disease for the years 2000, 2001 and 2002, which draw on a wide range of data sources to develop internally consistent estimates of incidence, health state prevalence, severity and duration, and mortality for over 130 major causes, for 17 sub-regions of the world. Estimates for 2002 are available on the WHO website referenced as WHO (2006). The two sub-regions², currently comprising 53% of the world's population, presented in this report are:

- ❑ The **Southeast Asian** region (SEARO) comprising (middle income) SEARO B which includes Indonesia, Sri Lanka and Thailand and (lower income) SEARO D which includes Bangladesh, Bhutan, Democratic People's Republic Of Korea, India, Maldives, Myanmar and Nepal; and
- ❑ The **Western Pacific** region (WPRO), comprising (higher income) WPRO A which includes Australia, Japan, Brunei Darussalam, New Zealand and Singapore; and (middle income) WPRO B which includes Cambodia, China, Lao People's Democratic Republic, Malaysia, Mongolia, Philippines, Republic Of Korea, Vietnam, Cook Islands, Fiji, Kiribati, Marshall Islands, Micronesia (Federated States Of), Nauru, Niue, Palau, Papua New Guinea, Samoa, Solomon Islands, Tonga, Tuvalu and Vanuatu.

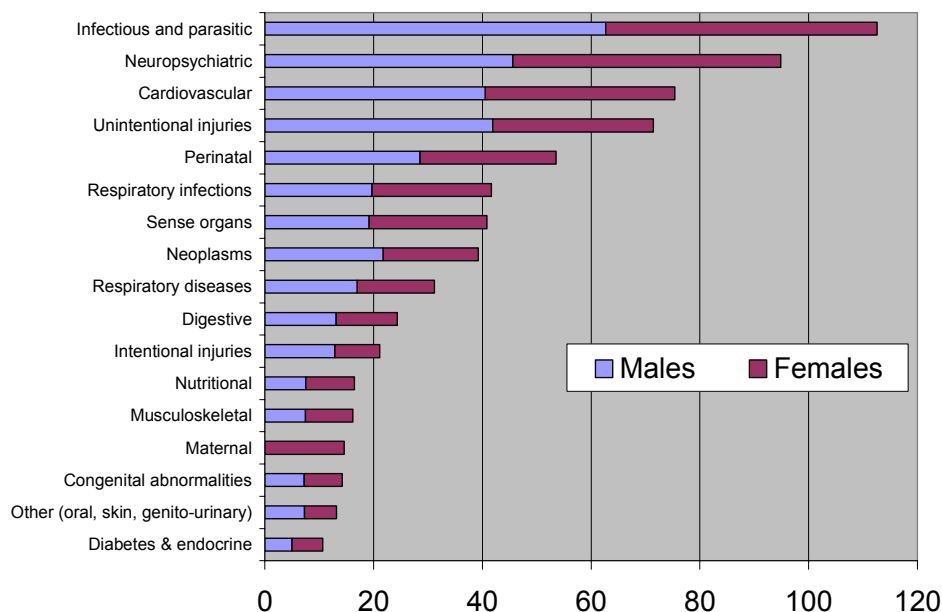
Figure 1-1 illustrates that, in this region, nearly 100 million DALYs are lost each year due to neuropsychiatric conditions³ the second highest source of disease burden after infectious and parasitic diseases, and higher than cardiovascular disease, injuries, perinatal disorders or cancer (neoplasms).

² Pakistan is an ADI member of the region but unfortunately is not included in the data for either the Western Pacific or Southeast Asian region by WHO.

³ Neuropsychiatric conditions comprise (in the WHO definition) Parkinson's disease, multiple sclerosis, drug use disorders, insomnia (primary), obsessive-compulsive disorder, post-traumatic stress disorder, epilepsy, panic disorder, migraine, other neuropsychiatric disorders, Alzheimer's and other dementias, mental retardation (lead-caused), bipolar disorder, alcohol use disorders, schizophrenia and unipolar depressive disorders.



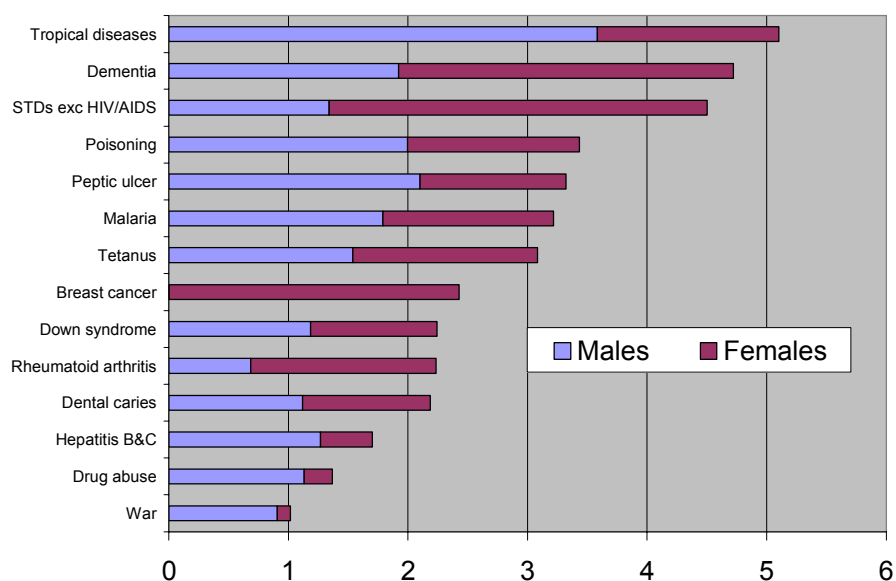
FIGURE 1-1: BURDEN OF DISEASE, MAJOR GROUPS BY GENDER, WPRO & SEARO, 2002, MILLION DALYS



Source: Based on data from WHO (2006).

Within neuropsychiatric disorders, dementia accounts for 5.0% of the burden of disease and ranks 6th, behind depression (the giant at 38.5%), schizophrenia, alcohol abuse, bipolar disorder and mental retardation (all between 5% and 10%). It is also revealing to compare dementia to other conditions with a similar magnitude of disease burden. This comparison is presented in Figure 1-2, showing similar disease burden for dementia to that of all tropical diseases in the Asia Pacific region, and greater burden of disease for dementia than for sexually transmitted diseases (excluding HIV/AIDS), poisoning, peptic ulcers, malaria, tetanus and breast cancer.

FIGURE 1-2: BURDEN OF DISEASE, DEMENTIA COMPARATORS, BY GENDER, WPRO & SEARO, 2002, MILLION DALYs

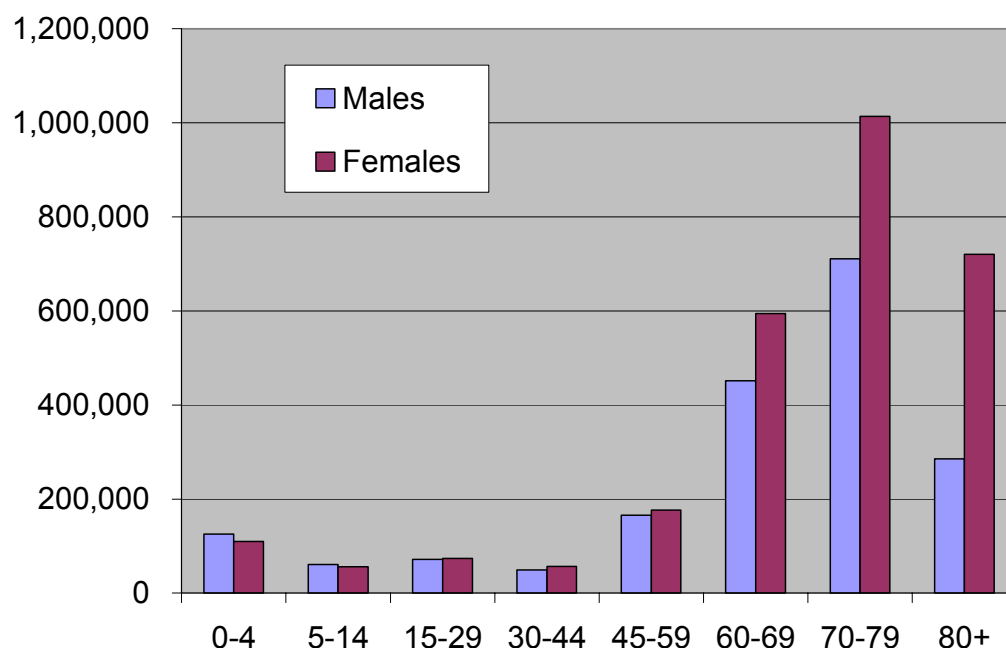


Source: Based on data from WHO (2006).



The regional age distribution of dementia's burden of disease is illustrated in Figure 1-3. Some 80% of the burden of disease is in those aged 60 years and over (compared to 10% of the region's population), and 58% in those aged 70 years (compared to 4% of population).

FIGURE 1-3: BURDEN OF DISEASE, DEMENTIA BY AGE, WPRO & SEARO, 2002, DALYs



In terms of the years of healthy life lost due to disability, dementia contributes 11.2% of years lived with disability in people aged 60 years and over – more than stroke (9.5%), musculoskeletal disorders (8.9%), cardiovascular disease (5.0%) and all forms of cancer (2.4%). The disability weight for dementia, estimated by international and multidisciplinary expert consensus, was higher than for almost any other health condition, apart from spinal-cord injury and terminal cancer (World Health Organization, 2003a).

1.3.2 WHO PROJECTIONS OF REGIONAL BURDEN OF DISEASE FROM DEMENTIA

The World Health Organization also projects the burden of disease from dementia and other causes over the next quarter century to 2030, based on average life expectancy as presented in Table 1-1, as well as other demographic and epidemiological variables. Female life expectancy at birth is projected to increase by 4.8 years for males and 8.2 years for females in the Southeast Asian region, while in the Western Pacific (reflecting overall higher life expectancy) the increases are 2.7 years and 4.6 years respectively. Gains for females are already greater than for males, driving an expectation that the burden of disease from dementia will be shouldered increasingly and disproportionately on women (from 60% to 65%, as shown in Table 1-2).



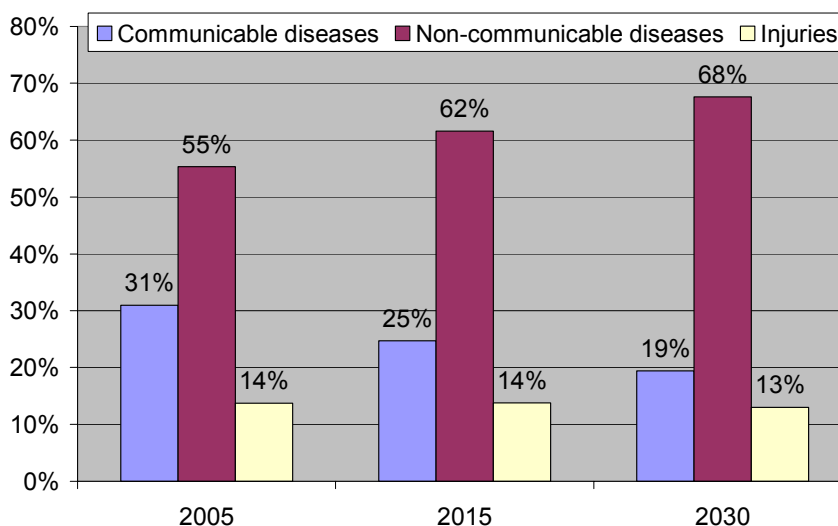
TABLE 1-1: PROJECTED LIFE EXPECTANCIES AT BIRTH AND AT AGE 60, BY GENDER AND REGION, 2002-30, YEARS

	Life expectancy at birth		Life expectancy at age 60	
	Male	Female	Male	Female
Southeast Asian Region				
2002	61.1	63.4	15.3	16.9
2030	65.9	71.5	16.7	19.3
Increase	4.8	8.2	1.4	2.4
Western Pacific Region				
2002	69.9	73.9	17.8	20.6
2030	72.6	78.5	19.0	22.6
Increase	2.7	4.6	1.2	1.9

Source: Mathers and Loncar (2006: Table 18).

As shown in Figure 1-4, burden of disease in the two Asia Pacific sub-regions from Group I causes (communicable, maternal, perinatal and nutritional conditions) are projected to fall from 31% of total burden of disease in 2005 to 19% in 2030. Burden of disease from injuries is projected to fall only slightly from 14% to 13%, while non-communicable diseases increase from 55% to 68% of the projected total. This latter category contains dementia, which also increases its share of the highest share group, from 1.4% to 1.9% (Table 1-2).

FIGURE 1-4: BURDEN OF DISEASE, WPRO & SEARO, BY GROUP, 2005-30, % TOTAL DALYS



Source: Based on WHO (2006). Note: Communicable diseases comprise communicable, maternal, perinatal and nutritional conditions.

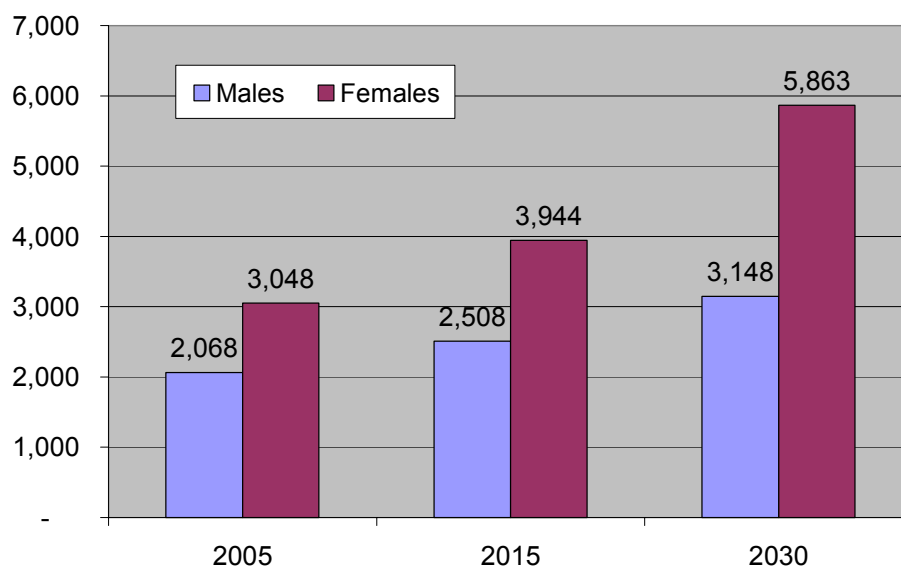


TABLE 1-2: BURDEN OF DISEASE, DEMENTIA, BY GENDER, WPRO & SEARO, 2005-30,
'000 DALYs

Year	Dementia prevalence			Female as % total	Dementia as % non-communicable	Dementia as % total burden of disease
	Persons	Males	Females			
2005	5,116	2,068	3,048	60%	1.4%	0.8%
2015	6,452	2,508	3,944	61%	1.5%	0.9%
2030	9,012	3,148	5,863	65%	1.9%	1.3%

The disease burden from dementia in the Asia Pacific region is expected to increase by 76% over the next quarter century (92% for women) – from 5.1 million to 9.0 million DALYs (Figure 1-5).

FIGURE 1-5: BURDEN OF DISEASE, DEMENTIA, BY GENDER, WPRO & SEARO, 2005-30,
'000 DALYs





2. PREVALENCE NOW AND TOMORROW

Prevalence refers to the number of people with dementia in a population at a given point, or over a certain period, of time. International epidemiological studies make it clear that dementia occurs in every country of the world.

2.1 PREVALENCE STUDIES

Prevalence studies give slightly different results depending on the methods used in the study (ADI, 1999a), although all studies show a sharp rise in prevalence rates with age. Although dementia can occur at any age, it is rare below the age of 60 years. Because of population ageing, in the future there will be relatively more people in the age groups at most risk for dementia. In the absence of effective prevention or treatment, the increase in the numbers of people with dementia will come about as a simple consequence of an increase in the size of the population most at risk, ie of those aged 60 years and over.

2.1.1 EARLY ESTIMATES OF PREVALENCE RATES BY AGE GROUP

A statistical integration of results from a number of prevalence studies for people aged 65 and over provided rates rising from 1.4% in the 65-69 year age group to 23.6% in those aged 85 years and over (Jorm et al, 1987). These figures were derived from surveys in the more developed countries (Europe, North America, Australasia and Japan). A pooling of data from European studies gave very similar figures (Hofman et al, 1991). There is continuing controversy about the prevalence rates in extreme old age (90 years onwards). One view is that everyone will develop dementia if they live long enough, but there is an opposing view that the risk of developing dementia levels out, and may even decline in extreme old age (Jorm et al, 1991).

Gender differences: As noted in Section 1.2 in risk factors, some studies show a slightly higher prevalence rate of Alzheimer's disease in women. However, many studies show no gender difference in the overall prevalence of dementia.

Studies over time: Two population-based studies surveyed residents of the same area over long periods of time. The Swedish Lundby study (Roorsman et al, 1986) indicated no significant change in prevalence or incidence of either multi-infarct dementia or 'senile dementia' over 1947 to 1972. In Rochester in the US (Beard et al, 1991) the register suggested no change in the prevalence of either Alzheimer's disease or other dementias between 1975 and 1980.

2.1.2 REGIONAL DIFFERENCES IN STUDIES

Although Alzheimer's disease is the most common form of dementia in Caucasian populations, this may not apply to other national or ethnic groups. Jorm's and later research suggested that vascular dementia might be more and Alzheimer's less common in Japan and in the former USSR, although the overall prevalence of dementia in Japan is similar to elsewhere. The ratio of vascular dementia cases to



Alzheimer's disease cases in Japanese studies varies between 1:1 and 3:1, compared with a typical ratio of 1:2.5 for European and American studies⁴.

Dementia may be less common in rural than urban areas, and in developing rather than developed countries.

- ❑ Prevalence rates for dementia were unusually low in three Scandinavian studies surveying rural communities. Two other small studies have reported very strong associations between urban residence and Alzheimer's disease (Prince et al, 1994; Baker et al, 1993).
- ❑ Prevalence has been noted to be lower in developing countries (10/66 DRG, 2000), strikingly so in some studies (Chandra et al, 1998) although data from developing countries are sparse. Well-conducted studies in Kerala, India (Shaji et al, 1996) and China (Zhang et al, 1990) suggest similar prevalence rates for dementia to those seen in developed countries, but dementia seems to be very rare in Kashmir (Chandra et al, 1998), and among Cree native American Indians (Hendrie et al, 1993). The best evidence for a contrast between developing and developed countries comes from a study that compared directly, using the same methods, the age-adjusted prevalence of dementia in African Americans in Indianapolis (6.4%) with Africans in Ibadan, Nigeria (1.2%) (Hendrie et al, 1995).
- ❑ Ferri et al, 2005 suggest that factors that may underlie regional variations include: genes, environment, infectious agents, chemical neurotoxins, diet, vascular disease and its risk factors, lifestyles and interactions between genes and environment.

2.1.3 RECENT WORLD PREVALENCE STUDIES

Prince et al (1997) estimated a total of 18 million people with dementia worldwide, assuming the same prevalence in all regions. Wimo et al (2004) estimated around 25 million in 2000 rising to 63 million by 2030 and 114 million by 2050, assuming no geographic variation in age-specific prevalence rates.

Most recently, Alzheimer's Disease International convened an international group of twelve experts to review world literature to generate evidence-based estimates for the prevalence and incidence of people with dementia in all WHO world regions (Ferri et al, 2005). The regions are the Americas (AMRO), Europe (EURO), North Africa and Middle East (AFRO), Southeast Asia (SEARO) and Western Pacific (WPRO). These regions are further categorised into subgroups based on patterns of child and adult mortality from A (lowest) to E (highest). They used United Nations population estimates to produce estimates for all types of dementia for five age bands from 60 to 84 years and for those aged 85 years and over, for the years 2001, 2020 and 2040. Ferri et al's findings are presented in Table 2-1, and summarised in point form below.

- ❑ The majority of people with dementia live in the developing world: 60% in 2001 rising to 71% by 2040. The rate of increase in the number of people with dementia is predicted to be three to four times higher in developing than in developed regions.

⁴ This difference, if genuine and not just a reflection of different diagnostic practices, remains unexplained. Two American studies of older Japanese immigrants in Hawaii (White et al, 1996) and King County (Graves et al, 1996) observed a ratio of vascular dementia to Alzheimer's disease cases that was more typical of findings among European and American Caucasians.



- The study showed the highest prevalence of dementia in China and its developing Western Pacific neighbours (6 million in 2001 increasing to 26.1 million), ahead of Western Europe (4.8 million increasing to 9.9 million) and North America (3.4 million increasing to 9.2 million).
 - The Asia Pacific region countries start with a large number of people with dementia and will experience rapid growth. Throughout this region, numbers of people with dementia will at least triple between now and 2040.
 - By contrast, developed regions also start with a large number of people with dementia but will experience a moderate proportionate increase (100% between 2001 and 2040), while in Latin America and Africa, prevalence starts with a low number of people with dementia but with a rapid increase in prevalence. The number of people with dementia will double in some areas and triple in others between now and 2040.

TABLE 2-1: DEMENTIA PREVALENCE 2001, 2020, 2040 BY WHO REGION

	Consensus dementia prevalence (%) (60+)	New dementia cases (millions) per annum, 2001	Numbers of people (millions) with dementia, aged 60+			Proportionate increase (%) in numbers of people with dementia	
			2001	2020	2040	2001-2020	2001-2040
Western Europe – EURO A	5.4	0.79	4.8	6.9	9.9	43	102
Eastern Europe low adult mortality – EURO B	3.8	0.21	1.0	1.6	2.8	51	169
Eastern Europe high adult mortality – EURO C	3.9	0.36	1.7	2.3	3.2	31	84
North America – AMRO A	6.4	0.56	3.4	5.1	9.2	49	172
Latin America –AMRO B/D	4.6	0.37	1.8	4.1	9.1	120	393
North Africa & Middle East EMRO B/D	3.6	0.21	1.0	1.9	4.7	95	385
Developed Western Pacific – WPRO A	4.3	0.24	1.5	2.9	4.3	99	189
China & developing Western Pacific – WPRO B	4.0	1.21	6.0	11.7	26.1	96	336
Indonesia, Thailand & Sri Lanka – SEARO B	2.7	0.14	0.6	1.3	2.7	100	325
India & S Asia – SEARO D	1.9	0.40	1.8	3.6	7.5	98	314
Africa – AFRO D/E	1.6	0.11	0.5	0.9	1.6	82	235
TOTAL	3.9	4.6	24.3	42.3	81.1	74	234

Source: Ferri et al (2005).

The prevalence rates for the region of interest are provided in Table 2-2 below.

TABLE 2-2: DEMENTIA PREVALENCE RATES, BY AGE GROUP, WPRO AND SEARO, %

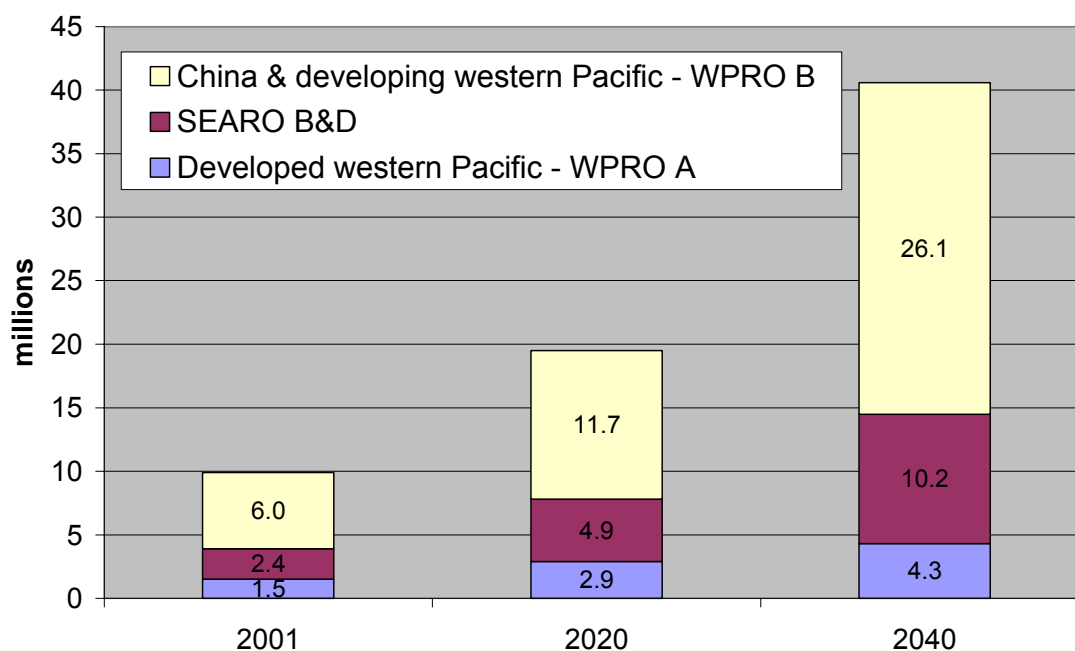
	60-64	65-69	70-74	75-79	80-84	>85
WPRO A	0.6	1.4	2.6	4.7	10.4	22.1
WPRO B	0.6	1.8	3.7	7.0	14.4	26.2
SEARO B	1.0	1.7	3.4	5.7	10.8	17.6
SEARO D	0.4	0.9	1.8	3.7	7.2	14.4

Source: Ferri et al (2005).

Regional prevalence is expected to increase from 9.9 million in 2001 to 40.6 million in 2040 (Figure 2-1).



FIGURE 2-1: DEMENTIA PREVALENCE, WPRO & SEARO, 2001, 2020, 2040



Source: Ferri et al (2005).

The authors noted the following cautions in relation to the estimates (Ferri et al, 2005:2116).

'First, these relied on demographic statistics, which might not be accurate for many parts of the world, especially for older age-groups. Second, we assumed that age-specific prevalence in each region would remain constant over time. In fact, changes in risk exposure might increase or decrease incidence. Improved medical and social care might reduce case mortality and increase prevalence... Methodological factors might also be relevant; mild dementia could have been under-detected in the least developed regions because of difficulties in establishing social impairment.'

2.2 REGIONAL PREVALENCE AND INCIDENCE ESTIMATES

For this report, dementia incidence and prevalence have been estimated for each country in the region and in total, using age-gender rates from meta-analysis (see next section) together with United Nations demographic data.

2.2.1 PREVALENCE AND INCIDENCE RATES USED IN THIS STUDY

The meta-analysis (Wancata et al, 2003) included studies by Jorm et al (1987), Hofman et al (1991), Ritchie and Kildea (1995) and Lobo et al (2000), with the average rates derived shown in Table 2-3. These rates fall within the ranges estimated by Ferri et al (2005) for the Western Pacific and Southeast Asian regions (Table 2-2).



TABLE 2-3: PREVALENCE AND INCIDENCE RATES, BY AGE AND GENDER, THIS STUDY, %

Age	Prevalence		Incidence	
	Male	Female	Male	Female
0-59	0.01	0.01	0.01	0.01
60-64	1.2	0.6	0.1	0.1
65-69	1.7	1.3	0.4	0.4
70-74	3.5	3.3	0.9	0.9
75-79	5.8	6.3	2.0	2.1
80-84	11.8	12.6	3.8	3.9
85-89	18.6	21.5	6.2	6.6
90-94	31.1	33.3	9.6	10.6
95+	38.1	40.3	8.7	8.7

2.2.2 UNITED NATIONS DEMOGRAPHIC DATA

United Nations demographic data was downloaded for the year 2005 and subsequent years to 2050, for each country in the region, by age group and gender. Countries able to be included were limited by data availability. United Nations data were available for:

- Australia, Bangladesh*, Bhutan*, Brunei Darussalam*, Burma*, Cambodia*, China, China (Hong Kong), China (Macao), TADA Chinese Taipei, Democratic People's Republic of Korea, East Timor (Timor Leste)*, India, Indonesia, Japan, Laos*, Malaysia, Nepal*, New Zealand, Pakistan, Papua New Guinea*, Philippines, Republic of Korea, Singapore, Sri Lanka, Thailand and Vietnam*.
 - Countries asterisked above are not ADI members.
- Note that, relative to the two regions defined in the WHO data, the United Nations data include Pakistan and East Timor (Timor Leste) and separately present Hong Kong. However, unlike WHO, they exclude the Maldives, Mongolia, Cook Islands, Fiji, Kiribati, Marshall Islands, Micronesia (Federated States Of), Nauru, Niue, Palau, Samoa, Solomon Islands, Tonga, Tuvalu and Vanuatu.
- Demographic data for TADA Chinese Taipei were provided by stakeholders.

2.2.3 RESULTS – 2005 TO 2050

Prevalence of dementia for these regional countries is estimated as 13.7 million people in 2005, rising to 64.6 million by 2050 (Figure 2-2).

- These estimates are of similar order of magnitude as the Ferri et al (2005) ones, bearing in mind that their estimates of 9.9 million for 2001 and 40.6 million 2040 were for earlier years, and exclude Pakistan (while including the smaller South Pacific Island countries). Moreover, they use slightly lower estimates of prevalence rates for SEARO D countries, which include populous India.

Incidence of dementia in the region is projected to increase from 4.3 million new cases per year in 2005 to 19.7 million new cases by 2050 (Figure 2-3).



FIGURE 2-2: TOTAL PREVALENCE, CHINA, INDIA AND OTHER REGIONAL, 2005-50

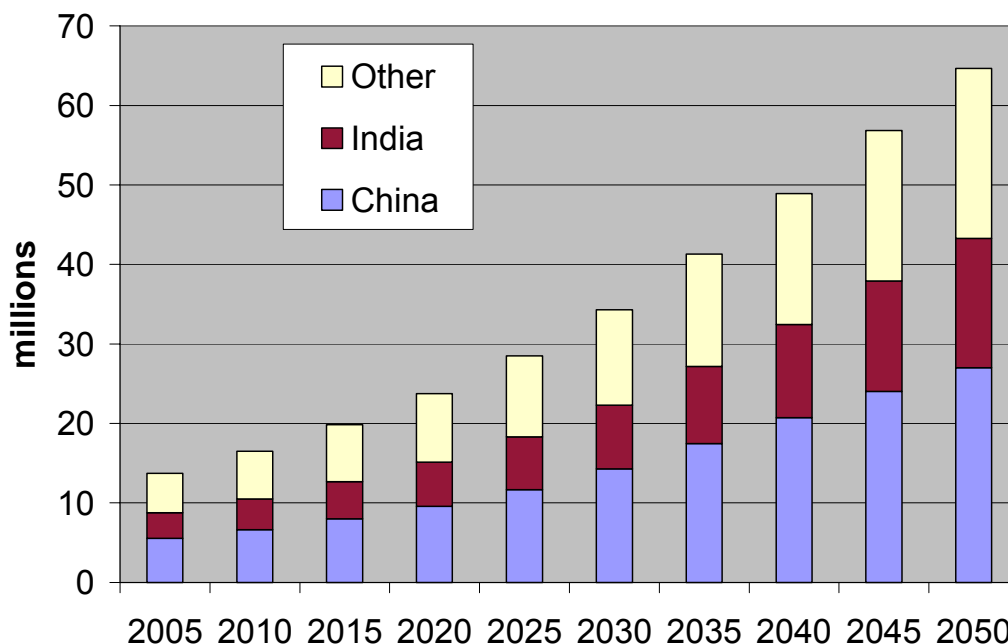
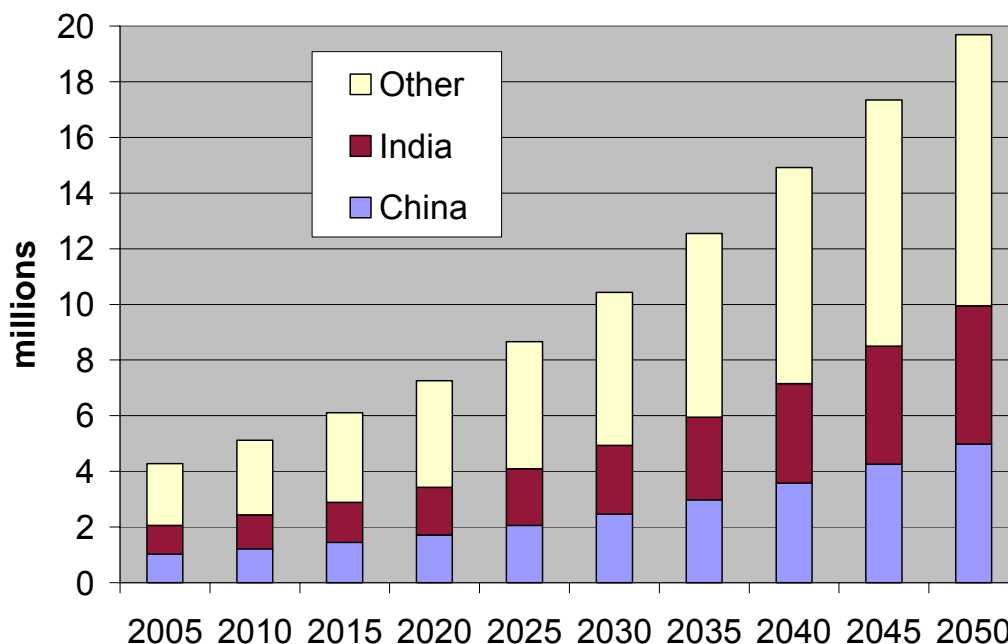


FIGURE 2-3: TOTAL INCIDENCE, CHINA, INDIA AND OTHER REGIONAL, 2005-50



Those projections assume, of course, that the prevalence rate of dementia does not change in the future. The prevalence rate of dementia might become lower, for example, if some means of preventing dementia were discovered. The prevalence rate might also conceivably increase if, for example, better care of people with dementia meant that they survived longer.



TABLE 2-4: PREVALENCE AND INCIDENCE, ASIA PACIFIC REGION, 2005-50, SUMMARY

Total region	2005	2010	2020	2030	2040	2050
Population (000s)	3,583,521	3,775,813	4,130,296	4,384,326	4,544,051	4,618,051
Prevalence (000s)	13,704	16,496	23,727	34,311	48,904	64,642
Incidence (000s)	4,282	5,123	7,262	10,427	14,920	19,687
Prevalence rate (%)	0.38	0.44	0.57	0.78	1.08	1.40
Incidence rate (%)	0.12	0.14	0.18	0.24	0.33	0.43

The proportion of people with dementia will increase from 0.38% of the total regional population to 1.4% over the next 45 years.

Individual country data for prevalence and incidence of dementia are summarised in the table below.

TABLE 2-5: PREVALENCE AND INCIDENCE, ADI ASIA PACIFIC REGION AND NON-ADI ASIA PACIFIC REGION

	2005		2020		2050	
'000 people	Prevalence	Incidence	Prevalence	Incidence	Prevalence	Incidence
Australia	195.4	60.2	301.3	91.1	664.1	199.7
China (inc Macao)	5,541.2	1,721.0	9,596.3	2,916.7	27,004.4	8,269.0
Hong Kong SAR	59.7	18.5	109.2	32.6	332.0	99.6
India	3,248.5	1,026.8	5,541.8	1,714.4	16,290.1	4,974.6
Indonesia	606.1	191.4	1,016.8	314.1	3,042.0	932.0
Japan	1,871.2	570.2	3,251.3	983.4	4,873.1	1,417.7
Malaysia	63.0	20.1	126.8	39.0	453.9	138.8
New Zealand	38.2	11.8	54.6	16.6	117.6	35.5
Pakistan	330.1	107.3	566.6	179.3	1,916.2	584.3
Philippines	169.8	54.8	316.3	99.2	1,158.9	353.9
Singapore	22.0	6.8	52.6	15.7	186.9	56.7
South Korea	246.3	75.5	542.2	164.3	1,569.9	475.4
Sri Lanka	86.0	26.9	148.0	45.1	409.0	125.0
TADA Chinese Taipei	138.0	43.1	253.4	76.6	659.3	199.4
Thailand	229.1	71.4	450.2	137.2	1,233.2	377.0
ADI Asia Pacific	12,844.3	4,005.9	22,327.6	6,825.2	59,910.6	18,238.7
Non-ADI Asia Pacific	859.3	276.2	1,399.6	437.1	4,730.9	1,448.6
Total region	13,703.6	4,282.1	23,727.1	7,262.3	64,641.5	19,687.3



3. ECONOMIC AND SOCIAL IMPACTS

Over half of the world's population lives in the Asia Pacific region. The previous chapter highlighted the impact of **demographic ageing**, driven by lower infant mortality rates and higher longevity, on the regional population, which will increase from 3.6 billion in 2005 to 4.6 billion by mid-century. Those aged over 60 years will increase from under 10% to 25% of the total, and those over 80 years will increase from 1% to 5% of the population. This will, in turn, underlie an increase in the prevalence of dementia from 13.7 million people to an estimated 64.6 million.

Other trends will exacerbate the economic impact of dementia.

- ❑ **Urbanisation** often involves young people moving away from agricultural villages, with elderly people left behind, and many become lonely and unsupported.
- ❑ There are also trends **away from extended families and towards nuclear families**, with the number of elderly people who live in the same household as their children declining in every country which records these figures. More ready acceptance of divorce fragments families further and may reduce the ties between elderly people and their adult children. More women are returning to work once their children reach school age, and have less ability to provide care.
- ❑ Increasingly, the **elderly live on their own** - between 30% and 40% in most Western countries, compared with around 10% in the mid twentieth century, a rapid and enormous social change towards single-person households. As a general rule, elderly people in Western societies value their independence and regard both sharing with their children and institutional care as inferior outcomes to continuing to live in their own home. These trends are now beginning to appear throughout the developing world also, with serious implications for health and welfare services and, particularly, the care of elderly people with dementia.

These trends suggest a growing pressure on family carers, and a greater likelihood that for many elderly people there will simply be no relatives around to provide care.

Dementia care is a mix of family (or informal) and professional or paid (formal) care giving and different nations have vastly different health care systems and patterns of care. Even among the wealthier economies, there is a great range in how dementia care is provided, due to differences in family patterns, traditions, economic strength, care organisation and financing. In recognition of the dimensions of the dementia epidemic, South Korea and Australia have made dementia a health priority and adopted an integrated strategy to address it. The Ministry of Health in Singapore has established a comprehensive and integrated blueprint on dementia care and the strategies include forming a dementia network that will co-ordinate services, training, research, improve collaboration and facilitate early identification and diagnosis. Unfortunately, most countries in the Asia Pacific region are still not well prepared to provide quality health and care services for people with dementia (Chiu and Chiu, 2005).

3.1 HEALTH CARE SERVICES

In most developed countries, the advice sought by people with dementia and their families is initially medical. People expect to be diagnosed by a doctor but assessment



can be problematic dependent on the training and experience of doctors. Often if symptoms become more marked, the patient is referred to a specialist, such as a neurologist, psycho-geriatrician or geriatrician.

In developing countries, doctors are scarce and specialists rare. Elderly people and their relatives may be less willing to consult them with problems such as failing memory, deteriorating speech or increasingly bizarre behaviour because mental illness may be feared and stigmatised. A particular challenge is to distinguish dementia from depression in those with low education levels (10/66 DRG, 2003).

Cultural responses to dementia symptoms and types may vary. For example, in India cases of dementia involving anger may be more easily recognised than those involving forgetfulness (Cohen, 1995). In China, medical help may be sought after a stroke, but not in response to failing powers of memory (Liu et al, 1994). It is widely held that symptoms of dementia such as deteriorating memory, if present without signs of physical deterioration, may be dismissed simply as the inevitable consequence of old age (Chandra et al, 1994).

Providing appropriate help from medical and social welfare services may be hindered if people with dementia and their relatives are unaware of what help is available, or if they perceive it as not appropriate for them; or if the service-provider remain ignorant of their needs. Difficulties of service delivery are particularly likely for people who have been international migrants, and most acute for those who do not speak the national language. Many countries in the region now contain substantial numbers of such people, who may revert more to their original language as dementia progresses.

3.2 INFORMAL FAMILY CARE

Research has shown that family care givers remain the cornerstone of support for people with dementia, who generally live in their own homes and are cared for by a female care giver, usually a spouse or a daughter.

In developing countries caring is associated with substantial psychological, practical and economic strain (10/66 DRG, 2004a). This is because:

- ❑ Very few care givers receive any allowance or benefit related to this care.
- ❑ Few people with dementia have access to pensions or receive any disability allowance.
- ❑ A substantial proportion of care givers have to give up work.
- ❑ Increased expenditures are incurred for health services.
- ❑ The combination of reduced income and increased cost results in stress for households who exist at or near to subsistence level.

In developed countries, notwithstanding better access to services, family care givers provide the greater part of care. The physical, emotional and economic costs of caring translate again into carer stress. In the USA, the annual cost of informal care was estimated as US\$18 billion per year in 1998 US dollars (Larger et al 2001). In Australia, the replacement cost of informal care was estimated as nearly one third of the total real costs of dementia of A\$5.6 billion in 2003.

Faced with increased numbers of those who will require care, a critical issue across the region is the future supply of informal family carers as a consequence of a mix of



factors including trends away from extended families, increased female workforce participation and changing attitudes. This will increase the pressure for financial support for family carers, as well as for better support of family carers through well planned community care services such as carer education, support and respite services which give the family carer information and time to themselves.

3.3 COMMUNITY CARE

Community care services are the foundation on which is built the possibility of supporting older people in their homes and their family carers in the often stressful task of providing much of the care. The reality is starkly different in developing and developed countries.

In developing countries, the challenge is to design sensible interventions in circumstances where dementia is a hidden problem and health care services may not be oriented or resourced to meet the needs of people with dementia and their family carers. The approach adopted by the 10/66 Research Group (www.alz.co.uk/1066/) is to identify cases of dementia in the community; to determine a means of delivering the intervention in a home setting using existing resources and to have regard to the resources available. Elements of an approach to address those needs may include training for workers in the identification of those with dementia, the identification of workers able to undertake such work and who have the trust of the community, and the provision of basic education to care givers about the management of dementia including problem behaviours.

In developed countries, government policy generally embraces the principle of giving the aged person the choice of remaining in their own home for as long as possible, avoiding premature entry to expensive residential care. As a consequence, the funding for community services has increased as has the range of services available. Such services can empower the person with dementia and their care givers through information, education, counselling and support groups. Also they can directly assist in care through provision of meals and assistance with activities of daily living (eating, showering and mobility), home cleaning, nursing and respite care. In practice, access to these publicly provided services is rationed through capped funding. Apart from availability, a key issue in the provision of community services is how to achieve the flexibility necessary to respond to the particular needs of the person with dementia and their care givers through effective coordination of services and well trained workers. Trained volunteers often provide an important contribution to the provision of community services.

3.4 RESIDENTIAL CARE

Residential care is generally a prominent feature of care for frail older people in developed countries. An informal survey done by the Ministry of Health in Singapore of 6,492 residents in nursing homes in 2004 showed that 26.4% had been diagnosed as dementia and 8.6% were possible dementia cases. In Australia, around a quarter of men and nearly half of women aged 65 can expect to enter residential aged care at some point in their lifetime (Mason et al, 2001).

There has been a trend in developing countries away from institutional to home-like environments. Mainstream residential services may care for people with a range of complex nursing needs and reduced cognitive capacity and require well trained staff. Others may provide special services for those with severe behavioural and



psychological symptoms of dementia and employ specially trained staff. Design features for any residential care service for people with dementia will need to compensate for the cognitive changes of dementia and will “maximize awareness and orientation, promote feelings of, and actual safety and security, provide opportunities for significant social contact, and support functional ability through meaningful activity”. (Cohen and Wiseman, 1991).

Pressure for admission to residential care can be very strong. There is some evidence of a high rate of institutionalization of older people with dementia in some Asian cities (Chiu et al, 1998) possibly reflecting the breakdown of traditional family support.

The extent of dementia and cognitive impairment among elderly people in residential care is very considerable. Figures from Japan, Australia, the USA and Europe report that in residential institutions for the elderly, between 42% and 66% suffer from moderate or severe cognitive impairment (Fries et al, 1997; Jagger and Lindesay, 1997). At least 60% of Australia’s nursing home (high level care) residents and 30% of hostel (lower level care) residents have dementia, while more than 90% and 54% respectively have a mild, moderate or severe cognitive impairment (Rosewarne et al, 1997; 2000).

While the populations of some countries continue to find the practice of segregating their elderly impractical or culturally unacceptable, there are strong indications that demand grows when economies begin to boom, elderly people accumulate wealth, and younger families are less able or willing to care for them.

3.5 COSTS

Economic costs of dementia can include a range of cost elements including:

- ❑ **health system costs** – hospital, primary care, specialist medical services, pharmaceuticals, diagnostic imaging, allied health services, health research, public health awareness;
- ❑ **care services** – whether provided by in the home or in residential accommodation – including recurrent expenditure and capital facilities;
- ❑ **productivity losses**, especially for people with early onset forms of dementia who may have to stop work because of their dementia;
- ❑ **aids, equipment and home modifications** – eg memory aids, bathing and toileting aids, safety aids, adapted cutlery and common items such as clothing, daily pill boxes, mobility/transport aids, nursing aids; and
- ❑ **the deadweight losses of government transfer payments**, including the distortions and administration costs of taxation revenue foregone and additional welfare payments, which can be large in developed economies in particular.

The worldwide ‘direct’ cost of dementia is estimated at around US\$156 billion, based on a worldwide prevalence estimate of 27.7 million people with dementia and cost-of-illness studies from key countries relating direct costs of care and gross domestic product (GDP) per capita (Winblad, 2005). Currently, 92% of the total worldwide costs of dementia care were found in what the researchers termed “the advanced economies,” which contain 38% of the prevalence.

For the 15 Asia Pacific region ADI members, Wimo et al (2006b) have estimated the cost of dementia as \$60.4 billion (in 2003 US dollars) for an estimated 12.6 million



people with dementia (almost half of their estimates of the worldwide dementia population), based on a costing model rather than exact calculations⁵. In the region, 70% of the total regional costs of dementia care were estimated to be in the advanced economies, which contain 18% of the prevalence.⁶

- ❑ Of this \$33.6 billion are the estimated “direct” costs. The methods for the direct cost estimation are detailed in Wimo et al (2006a). The direct cost model is based on a selection of dementia health cost data from countries where they are available. The relation between these costs and GDP per capita is estimated and imputed, with various adjustments, to the other countries where no data are available.
- ❑ The remaining \$26.8 billion are the estimated costs of informal care. The base case of the cost model of informal care uses a conservative estimate of the amount of informal care for people with dementia living at home (in terms of personal activities of daily living) multiplied by the average wage in different countries of the world (ie, a replacement valuation method).

Costs are projected to increase as prevalence grows for regional economies. In Australia, the real financial costs of dementia are already around 1% of GDP and are likely to exceed 3.3% of GDP by mid-century (Access Economics, 2003). The expected increase in costs, for both Governments and the rest of society, given the projected increase in dementia prevalence in developing countries, presents a great challenge for their resource-constrained social and healthcare systems. However, a glimpse of future impacts and lessons learned can be gained from regional countries further along the demographic ageing transition, such as Japan, Singapore, Australia and New Zealand.

In particular, scientists, advocates and those affected by dementia are calling for increased funding for research and support services, in the hope of finding a way to reduce dementia incidence, delay onset, or find more cost-effective means of treatment and care. One study (Access Economics, 2004) found that if the average onset of Alzheimer’s disease could be delayed in 2005 by:

- ❑ 5 months, there would be a 5% reduction in new cases each year, resulting in 3.5% fewer cases by 2020 and 4.8% fewer cases by 2040, with a cumulative savings by then of nearly twice the total annual costs in 2005.
- ❑ 5 years, there would be a 50% reduction in new cases each year, resulting in 35.2% fewer cases by 2020 and 48.5% fewer cases by 2040, with a cumulative savings by then of nearly 20 times the total annual costs in 2005.

If dementia onset can be delayed, this reduces the average number of years spent living with the condition (assuming that overall life expectancy remains constant). As a consequence, there tend to be fewer people living with dementia over prolonged

⁵ For example, as a consequence of the assumptions, Japan, a strong economic nation with a high GDP per person, high average wage and many people with dementia, accounts for 57% of the modelled costs of the total 15 ADI members. The prevalence figures are based on demographic data and prevalence rates from meta-analyses for age class prevalence Fratiglioni and Rocca (2003). Wimo et al (2006a) varies the prevalence in the sensitivity analysis. Costs are converted to US dollars at 2003 purchasing power parities.

⁶ The ‘advanced’ economies comprised Australia, China (Hong Kong), Japan, New Zealand, Republic of Korea, Singapore and TADA Chinese Taipei. Prevalence estimates were those of Wimo et al.



periods. As health services and dementia costs tend to be higher for these people than for newly diagnosed individuals, the cost savings of prevention may potentially be even greater than estimated above.

Recent developments in neuroscience, genetic and medical technology suggest that prevention in terms of slowing the progression of dementia is possible. However, there is a need for further research and, in particular, large randomised prevention trials, before the potential gains of delay in the onset can be quantified. If any of these or other future prevention strategies could delay the onset of dementia even modestly, the total years of disabled life and disease burden due to dementia may be significantly reduced, with associated substantial public health resource allocation implications.

The next chapter briefly explores other options for providing cost-effective solutions.





4. COST EFFECTIVE INTERVENTIONS

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

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

The progression of dementia, the variety of causes and differences in individual circumstances prevent any mechanical approach to treatment. Rather, a model of severity by types of care for patients with behavioural and psychological symptoms of dementia (see the “Brodaty Triangle” diagram in the Appendix) illustrates the different levels of management that need to be in place. The triangle was developed in Western countries so may not be directly translatable to the developing countries of the region, while still providing useful insights.

4.1 THE IMPORTANCE OF ECONOMIC ANALYSIS AND COST-EFFECTIVENESS STUDIES

Faced with the growing prevalence and costs of dementia, it is important for Governments and care providers in the Asia Pacific region to manage scarce resources in a way that best provides for people with dementia in the future – optimising wellbeing for people with dementia and their care givers at an appropriate level of cost.

In order to select the most appropriate models of care, a valuable tool is provided by economic studies that assess the “cost-effectiveness” of various interventions.

- Cost-effectiveness evaluations measure the dollars required to purchase a year of healthy life and are measured in terms of “dollars per quality adjusted life year” (\$/QALY). Other currency measures can also be used.
- Interventions that, overall, save both “dollars” and healthy life are defined as *cost-saving* or *dominant* therapies.

If one intervention has a lower \$/QALY than another, it would offer a more efficient approach than its comparator. Naturally, other criteria as well as efficiency are important in order to determine how resources are spent on dementia care. Equity of access is also important, so that people in remote areas, for example, can receive the same services as those in urban areas, although it might cost more to provide the same services in remote locations. Quality and sustainability might be other criteria to consider in determining how to allocate resources for dementia care.



Another key consideration is to what extent services should be subsidised or reimbursed by Governments. There have been useful lessons learned in this respect by those nations that have travelled this path and conducted economic studies of appropriate thresholds that would represent 'good value' as an investment in health and wellbeing.

"While there is no accepted standard for what constitutes good value, the range from US\$50,000 to US\$100,000 per QALY has often been used as a rough benchmark for the United States... A value of £20,000 to £30,000 has been used in the UK (Devlin et al, 2004, based also on Hirth et al, 2000)."

Naturally the US benchmarks may not be appropriate in other places and would be expected to vary from country to country. However, it is important for each regional member to consider, measure and make decisions regarding the relative cost-effectiveness of different dementia care options, and to what extent the Government will reimburse their provision, armed with appropriate information and evidence from prior economic analysis and experience.

It is important because there are positive solutions and responses to the dementia epidemic. The next section presents a small subset of these.

4.2 COST EFFECTIVENESS OF PHARMACOLOGICAL AND NON-PHARMACOLOGICAL INTERVENTIONS

There is an accumulating literature on cost effectiveness of carer interventions, different modes of care, respite care and consultation approaches in relation to dementia, as well as on pharmacological interventions. Although many psychosocial and pharmacological/diagnostic interventions have been shown to be cost-effective, most studies tend to focus on medications.⁷

For example, cholinesterase inhibitors can help ameliorate the symptoms of dementia (eg, delaying the progression of symptoms of Alzheimer's Disease for nine to twelve months and possibly longer) although they do not reverse disease or prolong life (Lopez et al, 2002). Economic studies have shown that these pharmacotherapies may have three important impacts:

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

There are other beneficial effects – for example, using these drugs may save costs by reducing the use of other drugs such as antipsychotic medications, of reducing the need for other therapies (such as primary care visits, hospitalisations) and of enabling people to continue working.

⁷ For example, the Cost Effectiveness Analysis (CEA) Registry provides public electronic access to a database of the results of cost-effectiveness studies in the published literature. The Registry is located at the Center for the Evaluation of Value and Risk in Health at Tufts-New England Medical Center <http://www.tufts-nemc.org/cearegistry/>



Lopez et al (2002) 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.”

In addition to the evidence basis for the cost-effectiveness of various pharmacotherapies and for early diagnosis and intervention, there are also some important studies showing cost-effectiveness of interventions for carer education, training and support. For example:

- ❑ a meta-analysis of 34 care giver interventions from 30 studies showed that they reduced psychological morbidity and helped people with dementia stay at home longer, albeit with variation in outcomes depending on the modality of the intervention (Brodaty et al, 2003a);
- ❑ the Mittelman study from New York, showed that family carers of people with Alzheimer’s Disease who received family and individual counselling were able to give care for almost a year longer than those in the control group;
- ❑ based on this efficacy, support programs for family carers as delivered through the Early Stage Dementia Support and Respite Program in Australia, was estimated (Access Economics, 2003) to accrue returns around 7:1; and
- ❑ the study continues to make new findings on effective care giver interventions, such as reducing depression (Mittelman et al, 2004).

As illustrated in Section 3.5, however, the most cost-effective interventions are likely to be those that could delay the onset of dementia, potentially through new research.





5. POLICY CHALLENGES AND FRAMEWORKS

With the ageing of the population, the exponential increase in the number of people with dementia has become one of the major health challenges for health care systems. This comes at a time when economic and social changes have weakened traditional support mechanisms through family care giving. While there is some commonality in the policy issues that need to be addressed by all countries, in the Asia Pacific region the policy challenges faced by developing countries may be significantly more difficult.

- ❑ There is a **low awareness** of dementia as an illness, together with somewhat nihilistic acceptance, and misperceptions that it is a part of 'normal' ageing and irrevocably 'incurable', with no treatment possible. Thus, people with dementia are often diagnosed quite late, by which time their carers frequently may be under a lot of stress and not aware of the availability of any help.
- ❑ In most regional countries, there are **inadequate human and financial resources** and a **policy vacuum on dementia care**, as it is not yet seen as a health priority in many countries. With scarce resources, the 'urgent' (such as infectious conditions) may displace important long term issues such as dementia care.
- ❑ There is **inadequate training for formal carers** and a **lack of support for informal carers**.

In developed countries, a continuing policy focus is the increased provision of community care services both to prevent premature institutionalisation and to control the exploding cost of residential care services to governments. There is concern about the abuse of older people and the need to protect their rights as, for example, in the Elder Abuse Prevention Law that came into force in Japan in April 2006 and the measures being introduced by the Australian Government. Greater investment in dementia research is needed if more effective medical interventions are to be found.

5.1 2004 CONSENSUS STATEMENT

As a response to the very real problems associated with the impact of dementia in Asia, a consensus program on improving the quality of life for people with dementia (QoLDEM) was adopted in 2004. The Consensus Statement provides a useful best practice document both for workers in the field of dementia care and for policy makers to review current practice and to plan the way forward (Chiu and Chiu, 2005). The Statement is endorsed by the World Psychiatric Association, the International Psychogeriatric Association and the Pacific Rim College of Psychiatrists.

Noting the demographic drivers of the dementia 'explosion' projected for the region over the coming decades, signatories to the agreement warned that the development of infrastructure and programs for dementia care, awareness of dementia as a disease and the expectations of policy-makers regarding dementia, do not match the growth in projected prevalence.

5.2 PATHWAY OF DEMENTIA

The "pathway of dementia" is used to help raise the awareness in the community of the symptoms of dementia and to inform people of the positive aspects of what can be done to obtain positive outcomes (Naidoo and Bullock, 2001). The reasons for



developing .an integrated care pathway for dementia are to ensure a policy framework that focuses on early diagnosis of dementia, appropriate information for all those involved, care based on evidence, enabling individuals to remain independent and at home for as long as possible, and services responsive to the needs of the person with dementia and their family at all stages of dementia.

Pathways are a way of demonstrating from the perspective of a person with dementia and their family the decisions that need to be taken in respect of their care irrespective of where they may live.

Drawing on the Consensus Statement and other studies (Naidoo and Bullock, 2001; Grossberg and Abhilash, 2003) the pathway can be described in the following way.

5.2.1 PRE-DEMENTIA

Contributors to healthy ageing are a healthy lifestyle which includes a balanced diet, exercise, meaningful social activities and low stress. Population risk factors should be reduced including hypertension, hypercholesterolemia, smoking, diabetes, obesity, vascular diseases and heavy alcohol use. Taking antioxidants, optimising intellectual activities and treating psychiatric morbidity (eg, depression) should be part of this strategy. Research into possible interventions and the development of dietary and supplement guidelines are desirable. Strategies to achieve better quality of life will include: reduction of poverty, improved education, financial security, healthy accommodation and environment. The role of health promotion, health maintenance, quality health care programs and accessible transport is also important. Further, the enhancement of spirituality (meaning of life) in this period, with resulting life satisfaction, supported by health-promoting family values, satisfying friendships and recreational pursuits are seen to be valuable. A sense of usefulness in old age, aided by the participation in lifelong learning will assist in the maintenance of cognitive capacities as well as enjoyment of life.

5.2.2 EARLY DEMENTIA

Education of primary care physicians as well as specialists is crucial to early identification, diagnosis and treatment. Validated instruments for cognitive assessment should be used routinely by all physicians working with the elderly. The physician who makes the diagnosis of dementia should provide the person with dementia and carers with appropriate counselling and explanations of the diagnosis, course and prognosis of dementia, as well as any hereditary implications.

Early planning for the future of the person with dementia is important in all areas of life, including financial and legal arrangements, driving competence, lifestyle change, relationship with family members and psychological wellbeing. Support for carers should be planned and implemented at this early stage.

Ready access to affordable medications at this stage is essential and management of medical co-morbidity can have a significant positive impact. Home-based support, elderly day care, pursuing voluntary work and trans-generational activities with younger members of family and community will add to quality of life. Physical, psychological and financial abuse must be prevented, with the establishment of guardianship legislation providing a sound basis for abuse prevention.



5.2.3 MODERATE DEMENTIA

As the dementia progresses, behavioural and psychological symptoms of dementia are common and serious problems that affect the quality of life of the person with dementia and their care givers and, as a consequence, can result in premature institutionalisation. Strategies to prevent behavioural and psychological symptoms of dementia should be developed including through psycho-social approaches and medication. Medical co-morbidity must be identified and effectively treated, including under-nutrition, infections, infestation from unhealthy environments, the impacts of major surgery or anaesthesia, dental care, hearing and visual impairment, and gynaecological needs.

Safety issues for the person with dementia should be pursued. Many older people may continue to drive despite having impaired abilities. Families should be warned of the hazards of wandering and counselled on appropriate strategies. Families and care givers should be counselled on ways of modifying the place of living to reduce the risk of falls and reducing exposure to danger including through the removal of harmful substances and sharp objects.

The education of non-health-related professions such as the police, staff of shops, banks and restaurants should be undertaken to provide a more accepting, tolerant and supportive out-of-home environment. Medication education and compliance should be monitored, for prescribed as well as self-initiated (herbal or over-the-counter) medication. Reduction in care giver stress must be part of service delivery at this stage. Sudden, unexpected changes to familiar environments should be avoided; relocation of persons with dementia should be undertaken in planned stages accompanied by a program of familiarisation.

5.2.4 SEVERE DEMENTIA

In this late stage, effective management in the residential care setting or at home is important. The use of restraint should be avoided as a care option. The privacy, dignity and autonomy of the person with dementia must be constantly respected. Food should be provided for personal enjoyment as well as nutrition, as this may be of particular cultural importance. Quality nursing and personal care in quality places are essential, as is the appropriate use of medication, avoiding both over- and under- use. The care environment should be calm, reassuring and comfortable and respond to the spiritual needs of the person with dementia.

5.2.5 END-OF-LIFE ISSUES

A Living Will, matters of inheritance distribution and decisions regarding resuscitation should have been settled before capacity is lost. Quality palliative care should underpin all care at this stage to assist the person with dementia to die with dignity and comfort. There is a need for open debate about how to achieve these outcomes for the person with dementia and their families. The necessity for timely and effective bereavement counselling of family and staff members in care facilities should be established routinely, together with the need for culturally and religiously appropriate rituals before and after the death of the person with dementia.



5.3 THE KYOTO DECLARATION

In October 2004, the 20th International Conference of ADI was held in Kyoto, Japan. The conference drew to a close with ADI setting out the Kyoto Declaration – an action plan for dementia, based on the “Minimum actions required” outlined in WHO (2001). The challenge for the Region now is to put this plan (Table 5-1) into action.



TABLE 5-1: MINIMUM ACTIONS REQUIRED FOR THE CARE OF PEOPLE WITH DEMENTIA

Ten overall recommendations	Scenario A Low level of resources	Scenario B Medium level of resources	Scenario C High level of resources
1. Provide treatment in primary care	Recognise dementia care as a component of primary health care. Include the recognition and treatment of dementia in training curricula of all health personnel. Provide refresher training to primary care physicians (at least 50% coverage in 5 years).	Develop locally relevant training materials. Provide refresher training to primary care physicians (100% coverage in 5 years).	Improve effectiveness of management of dementia in primary health care. Improve referral patterns.
2. Make appropriate treatments available	Increase availability of essential drugs for the treatment of dementia and associated psychological and behavioural symptoms. Develop and evaluate basic educational and training interventions for care givers.	Ensure availability of essential drugs in all health care settings. Make effective care giver interventions generally available.	Provide easier access to newer drugs (eg anticholinesterase agents) under public or private treatment plans.
3. Give care in the community	Establish the principle that people with dementia are best assessed and treated in their own homes. Develop and promote standard needs assessments for use in primary and secondary care. Initiate pilot projects on development of multidisciplinary community care teams, day care and short term respite. Move people with dementia out of inappropriate institutional settings.	Initiate pilot projects on integration of dementia care with general health care. Provide community care facilities (at least 50% coverage with multi-disciplinary community teams, day care, respite and inpatient units for acute assessment and treatment). According to need, encourage the development of residential and nursing home facilities, including regulatory framework and system for staff training and accreditation.	Develop alternative residential facilities. Provide community care facilities (100% coverage). Give individualised care in the community to people with dementia.
4. Educate the public	Promote public campaigns against stigma and discrimination. Support nongovernmental organisations in public education.	Use the mass media to promote awareness of dementia, foster positive attitudes, and help prevent cognitive impairment and dementia.	Launch public campaigns for early help-seeking, recognition and appropriate management of dementia.
5. Involve communities, families and consumers	Support the formation of self-help groups. Fund schemes for nongovernmental organisations.	Ensure representation of communities, families, and consumers in policy-making, service development and implementation.	Foster advocacy initiatives.



6. Establish national policies, programs and legislation	Revise legislation based on current knowledge and human rights considerations Formulate dementia care programs and policies. - Legal framework to support and protect those with impaired mental capacity - Inclusion of people with dementia in disability benefit schemes - Inclusion of care givers in compensatory benefit schemes Establish health and social care budgets for older persons.	Implement dementia care policies at national and subnational levels. Establish health and social care budgets for dementia care. Increase the budget for mental health care.	Ensure fairness in access to primary and secondary health care services, and to social welfare programs and benefits.
7. Develop human resources	Train primary health care workers. Initiate higher professional training programs for doctors and nurses in old age psychiatry and medicine. Develop training and resource centres.	Create a network of national training centres for physicians, psychiatrists, nurses, psychologists and social workers.	Train specialists in advanced treatment skills.
8. Link with other sectors	Initiate community, school and workplace dementia awareness programs. Encourage the activities of nongovernmental organisations.	Strengthen community programs.	Occupational health services for people with early dementia. Provide special facilities in the workplace for care givers of people with dementia. Initiate evidence-based mental health promotion programs in collaboration with other sectors.
9. Monitor community health	Include dementia in basic health information systems. Survey high-risk population groups.	Institute surveillance for early dementia in the community.	Develop advanced monitoring systems. Monitor effectiveness of preventive programs.
10. Support more research	Conduct studies in primary health care settings on the prevalence, course, outcome and impact of dementia in the community.	Institute effectiveness and cost-effectiveness studies for community management of dementia.	Extend research on the causes of dementia. Carry out research on service delivery. Investigate evidence on the prevention of dementia.

“People tend to think the onset of dementia deprives you of everything, that you are lost. That’s not true. I wanted to send the message that I am getting on with my life, just like normal. My brain may be failing but I won’t be alone. I will continue to try and live out my life my own way.”

Mr Ochi, 73 years, speaking in Kyoto of his dementia diagnosis (pictured below).





5.4 ADI CALL TO ACTION 2005

With the release of the new global dementia prevalence estimates (Ferri et al, 2005) in December 2005, ADI presented a 'call to action' in response to what the press reported as 'a ticking time bomb' (Media release, Friday 16 December 2005).

There is already a great need for community based services, welfare and support and these new figures show that pressure on governments for dementia services will increase dramatically in the next few years. (ADI, 2005).

Lessons for policy-making, planning, and allocation of health and welfare resources are summarised below, focusing around four major themes.

- 1 **Primary prevention** should focus on targets suggested by current evidence: risk factors for vascular disease including hypertension, smoking, type 2 diabetes, and hyperlipidemia (Breteler et al, 1998). The epidemic of smoking in developing countries and the high and rising prevalence of type 2 diabetes in Asia are particular causes of concern. More work is needed to identify further modifiable risk factors.
- 2 **GPs/primary care:** For many low-income countries the most cost-effective approach will be community primary care to support and advise family care givers (Shaji et al, 2003; 10/66 DRG, 2004a,b; Patel and Prince, 2001). Day care and residential respite care are expensive but important elements of a community service. Residential care is unlikely to be a government priority, but private nursing and residential care homes are already opening to meet the new demand. If government policies are well formulated and planned with the projections described in this paper in mind, the inevitable shift of resource expenditure towards older people can be predicted and its consequences mitigated (Kalache, 1991). The health and social care needs of the large and rapidly growing numbers of frail, dependent older people should be a matter of great concern for policymakers in developing regions.
- 3 Achieving progress with **dementia care** in developing countries has much to do with creating the climate for change. Poor awareness is a key public health problem with important consequences: affected people do not seek help, and if they do, health care services tend not to meet their needs (10/66 DRG, 2004a); dementia is stigmatised, and sufferers can be excluded from residential care and denied admission to hospital (Shaji et al, 2003; 10/66 DRG, 2004b; Patel and Prince, 2001); no constituency is available to lobby government; and families tend to have less support or understanding from others and experience substantial strain (10/66 DRG, 2004a).
- 4 **NGOs (ADI):** National Alzheimer's associations help to raise awareness and create a framework for positive engagement between policymakers, clinicians, researchers, care givers, and people with dementia. Their advocacy, empowered by evidence of prevalence, effect and need, will help to foster the development of more responsive services.

5.5 RESEARCH

It has been 100 years since Alzheimer's disease was first described. However, it is only in the last 25 years that increased investment in research has made possible progress towards a better understanding of Alzheimer's disease and other forms of

dementia. What happens next will depend on an even greater commitment to research to slow the onset of dementia or even to find a cure.

Until more effective medical interventions are found, it is important to give priority to improving quality of life for people with dementia and their care givers, through improving care service and delivery, non-pharmacological approaches to management and a focus on the needs of special groups including, those with younger onset dementia. It is important in this work to establish a priority for the work of the 10/66 Dementia Research Group (www.alz.co.uk/1066/) in developing countries in its aims:

- To estimate the numbers of person with dementia in those countries which have not been studied.
- To use these studies to learn more about the causes of dementia.
- To describe care arrangements for people with dementia.
- To qualify the impact of providing care on care givers.
- To encourage the development of support services, and to test how effective they are.





6. CONCLUSIONS AND RECOMMENDATIONS

The Asia Pacific region countries already have over half of the world's population. Throughout this region, numbers of people with dementia will at least triple between now and 2050.

Well formulated and planned government policies, in collaboration with private and community organisations, can reduce the cost impacts of the projected prevalence growth through cost-effective interventions that deliver quality outcomes for people with dementia and their families.

Governments in the Asia Pacific region will assist people with dementia and their family care givers if they recognise that:

- Dementia is a health priority.
- Cost-effective interventions exist.
- Policy frameworks and plans support all sectors in making a difference for people with dementia and their families.

The 2004 Kyoto Declaration provides a practical way forward and the framework for a program of action for Governments, non-government organisations and other stakeholders. Some Governments have already announced national policies.

The Asia Pacific region countries already have over half of the world's population. Throughout this region, numbers of people with dementia will at least triple between now and 2050.

It is recommended that all Asia Pacific Governments:

- 1 Consider and adopt the Kyoto Declaration, in the light of their own demographic, cultural and health care contexts.
- 2 Develop individually tailored national strategies for dementia that:
 - Create the climate for change through greater awareness and destigmatisation of dementia.
 - Build effective constituencies and coalitions for partnership between policy makers, clinicians, researchers, care givers and people with dementia.
 - Promote the development of primary and community care services that are responsive to the needs of people with dementia and their family care givers.
 - Provide information on the adoption of lifestyles that may reduce the risk of dementia.
 - Make provision for special needs, including people with younger onset dementia, and people with behavioural and psychological symptoms of dementia (BPSD).
- 3 Promote investment in research for cause, prevention and quality dementia care.

The issue of dementia is significant enough to justify collaborative action between regional governments. This could take the form of an initial meeting of Ministers or policy makers to set a joint agenda or collaboration, for example, in the areas of research and service delivery.



REFERENCES

- 10/66 Dementia Research Group (2004a) Care arrangements for people with dementia in developing countries. *Int J Geriatr Psychiatry* 19:170–77.
- 10/66 Dementia Research Group (2004b) Behavioural and psychological symptoms of dementia in developing countries. *Int Psychogeriatr* 16:441–59.
- 10/66 Dementia Research Group (2000) Methodological issues in population-based research into dementia in developing countries: a position paper from the 10/66 Dementia Research Group. *Int J Geriatr Psychiatry* 15:21–30.
- Access Economics (2005) Dementia estimates and projections: Australian States and Territories. Report for Alzheimer's Australia, February.
- Access Economics (2004) Delaying the onset of Alzheimer's Disease: Projections and Impacts. Report for Alzheimer's Australia, August.
- Access Economics (2003) The Dementia Epidemic: Economic impact and positive solutions for Australia. Report for Alzheimer's Australia, May.
- Alzheimer's Disease International (2005) Dementia "set to quadruple" says Lancet report: Developing countries hardest hit. Media Release, 17 December.
- Alzheimer's Disease International (1999a) The prevalence of dementia, Factsheet 3, April 1999.
- Alzheimer's Disease International (1999b) The demography of ageing around the world, Factsheet 4, March.
- Alzheimer's Disease International (1999c) Caring for people with dementia around the world, Factsheet 5, June.
- Baker FM, Jordan B, Barclay L, Schoenberg 135 (1993) Risk Factors for Clinically Diagnosed Alzheimer's disease. *International Journal of Geriatric Psychiatry* 8, 379-385.
- Beard CM, Kokmen E, Offord K, Kurland LT (1991) Is the prevalence of dementia changing? *Neurology* 41:1911-1914.
- Bennett K (1997) Cultural issues in designing for people with dementia, in M Marshall (ed), *State of the Art in Dementia Care*, London: Centre for Policy on Aging, 164-9.
- Bowling A (1989) Contact with general practitioners and differences in health among people over 85 years, *J Roy Coll Gen Pract*, 39:52-5.
- Breteler MM, Bots ML, Ott A, Hofman A. Risk factors for vascular disease and dementia. *Haemostasis* 1998; 28: 167–73.
- Brodaty H, Green A, Koschera A (2003a) Meta-analysis of psychosocial interventions for care givers of people with dementia. *Journal of the American Geriatrics Society* 51(5):657-664.



Brody H, Draper B, Low L-F (2003b) Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery. *MedJAust*, 178:231-235

Caro JJ, Salas M, Ward A, Getsios D, Mehnert A, Caro JJ, Salas M, Ward A, Getsios D, Mehnert A. (2002) Economic analysis of galantamine, a cholinesterase inhibitor, in the treatment of patients with mild to moderate Alzheimer's disease in the Netherlands. *Dement Geriatr Cogn Disord*. 13(1):84-9.

Chandra V, Ganguli M, Pandav R, Johnston J, Belle S, DeKosky ST (1998) Prevalence of Alzheimer's disease and other dementias in rural India: the Indo-US study. *Neurology* 51:1000-08.

Chandra V et al (1994) Studies of the epidemiology of dementia: comparisons between developed and developing countries, *Ageing: Clinical and Experimental Research*, 6, 307-321.

Chiu HFK and Chiu E (2005) Dementia Care in Asia, *International Psychogenetics* 17.1, 1-2.

Chiu HFK et al (1998) Prevalence of dementia in Chinese elderly in Hong Kong. *Neurology*, 50:1002-1009.

Christen Y (2000) Oxidative stress and Alzheimer disease, *Am J Clin Nutr*, 71(2):621S-629S.

Cohen L (1995) Towards an anthropology of senility: anger, weakness and Alzheimer's in Banaras, India, *Med Anth Quart*, 9(3):314-334.

Cohen U, Wiseman GD (1991) *Holding on to Home Designing Environments for People with Dementia*, John Hopkins University Press, Baltimore.

Cooper B (1994) Health-care policy and planning for the demented: an international perspective, in Huppert FA et al (eds) *Dementia and Normal Aging*, London: Cambridge University Press, 519-551.

Cummings J (2001) Treatment of Alzheimer's disease, *Clin. Cornerstone* 3(4):27-39.

Devlin N, Parkin D (2004) Does NICE have a cost-effectiveness threshold and what other factors influence its decisions? A binary choice analysis. *Health Economics* 13(5):437-452.

Ferri CP, Prince M, Brayne C, Brodaty H, Fratiglioni L, Ganguli M, Hall K, Hasegawa K, Hendrie H, Huang Y, Jorm A, Mathers C, Menezes PR, Rimmer E, Sczuzufca M, for Alzheimer's Disease International (2005) Global prevalence of dementia: a Delphi consensus study. *The Lancet*. December. 366:2112-7.

Fratiglioni L, Rocca, WA (2001) Epidemiology of dementia, pp 193-215 in Boller F, Cappa SF eds (2001) *Handbook of Neuropsychology*, second edition, Amsterdam, Elsevier.

Fratiglioni L, Ahlbom A, Viitanen M, Winblad B (1993) Risk factors for late onset Alzheimer's disease: a population-based case-control study, *Ann Neurol* 33:258-266.



Fries BE et al (1997) Cross-national comparisons of nursing home residents, *Age and Ageing*, 26, Suppl 2.

Graves AB, Larson EB, Edland SD, et al (1996) Prevalence of dementia and its subtypes in the Japanese American population of King County, Washington state. The Kame Project. *Am J Epidemiol* 144;760-771.

Grossberg GT, Desai AK (2003) Management of Alzheimer's Disease, Review Article, *Journal of Gerontology*; April 58A(4):331.

Harvard Medical School (2002) Dietary Antioxidants May Decrease Risk of Alzheimer's disease, *Family Health Guide: Chapter Update - Brain and Nervous System*, available on www.health.harvard.edu, August.

Harvard Medical School (2001) Statins Associated With Lower Dementia Risk, *Family Health Guide: Chapter Update - Brain and Nervous System*, available on www.health.harvard.edu, October.

Hendrie HC, Osuntokun BO, Hall KS et al (1995) Prevalence of Alzheimer's disease and dementia in two communities: Nigerian Africans and African Americans. *Am J Psychiatry* 152:1485-92.

Hendrie HC, Hall KS, Pillay N et al (1993) Alzheimer's disease is rare in Cree. *Int Psychogeriatr* 5:5-14.

Hirth RA, Chernew ME, Miller E, Fendrick AM, Weissert WG (2000) Willingness to pay for a quality-adjusted life year: In search of a standard. *Medical Decision Making* 20:332-342.

Hofman A, Rocca WA, Brayne C et al (1991) The prevalence of dementia in Europe: a collaborative study of 1980-1990 findings. Eurodem Prevalence Research Group. *Int J Epidemiol* 20:736-748.

Ikeda S, Yamada Y, Ikegami N (2002) Economic evaluation of donepezil treatment for Alzheimer's disease in Japan. *Dement Geriatr Cogn Disord*. 13(1):33-9.

Ineichen B (1988) Cultural concepts of care, in A Wimo et al (eds), *Health Economics of Dementia*, Wiley, 99-111.

Jagger C, Lindesay J (1997) Residential care for elderly people: the prevalence of cognitive impairment and behaviour problems, *Age and Ageing*, 26:475-480.

Jorm AF (1991) Cross-national comparisons of the occurrence of Alzheimer's and vascular dementias. *European Archives of Psychiatry and Clinical Neuroscience* 240:218-222.

Jorm AF, Korten AE, Henderson AS (1987) The prevalence of dementia: a quantitative integration of the literature. *Acta Psychiatrica Scandinavica* 76:465-479.

Kalache A (1991) Ageing is a third world problem too. *Int J Geriatr Psychiatry* 6:617-18.



Kukull W, Larson E, Bowen J, McCormick W, Teri L, Pfanschmidt M, Thompson J, O'Meara E, Brenner D, van Belle G (1995) Solvent exposure as a risk factor for Alzheimer's disease: a case control study, *Am J Epidemiol*, 141:1059-1071.

Langa KM, Chernew ME, Kabeto MU et al (2001) National estimates of the quantity and cost of informal care giving for the elderly with dementia. *J Gen Intern Med* 16:770-78.

Lawton MP (1994) Quality of life in Alzheimer's Disease. *Alzheimer's Disease and Associated Disorders*, 8:138-150.

Liu HC et al (1994) Assessing cognitive abilities and dementia in a predominantly illiterate population of older individuals in Kinmen, *Psychol Med*, 24:763-770.

Lobo A, Launer L, Fratiglioni L, Andersen K, Di Carlo A, Breteler M et al (2000) "Prevalence of dementia and major subtypes in Europe: A collaborative study of population-based cohorts" *Neurology* 54(Suppl 5):S4-9.

Lopez O, Becker J, Wisniewski S, Saxton J, Jauffer D, Dekosky S (2002) Cholinesterase inhibitor treatment alters the natural history of Alzheimer's disease *Journal of Neurology, Neurosurgery and Psychiatry* 72:310-314.

Lyketsos C, Steinberg M, Tschanz J et al (2000) Mental and behavioural disturbance in dementia; findings from the Cache County Study on Memory in Aging, *American Journal of Psychiatry* 157:708-714.

Mason F, Liu Z, Braun R (2001) The probability of using an aged care home over a life time (1999-00). *Welfare Discussion Working Paper No 36 AIHW Cat No AGE21*, Canberra, AIHW.

Mathers CD, Loncar D (2006) Updated projections of global mortality and burden of disease, 2002-2030: data sources, methods and results. *Evidence and Information for Policy Working Paper*. World Health Organization, October 2005 revised January 2006, http://www3.who.int/whosis/burden%5Cestimates%5Cprojections%5Cprojection_s_working_paper.pdf

McMahon PM, Araki SS, Sandberg EA, Neumann PJ, Gazelle GS (2003) Cost-effectiveness of PET in the diagnosis of Alzheimer disease. *Radiology*. 228(2):515-22.

Mittelman MS, Roth DL, Coon DW, Haley WE (2004) Sustained Benefit of Supportive Intervention for Depressive Symptoms in Care givers of Patients With Alzheimer's Disease," *American Journal of Psychiatry*, 161:850-856.

Murray C, Lopez A (1996) *The Global Burden of Disease: a comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990 and projected to 2020*", Volume 1, *Global Burden of Disease and Injury Series*, Harvard: Harvard School of Public Health.

Naidoo M, Bullock R (2001) *An Integrated Care Pathway for Dementia*, Kingshill Research Centre.

Neumann PJ (2005) *Using cost-effectiveness analysis to improve health care: Opportunities and barriers*. Oxford University Press: Oxford, 157-158.



Patel V, Prince M (2001) Ageing and mental health in a developing country: who cares? Qualitative studies from Goa, India. *Psychol Med* 31:29–38.

Prince MJ (1997) The need for research on dementia in developing countries. *Trop Med Health* 2:993–1000.

Prince MJ, Cullen MC, Mann AH (1994) Risk factors for Alzheimer's disease and dementia: A case-control study based on the MRC Elderly Hypertension Trial. *Neurology* 44, 97-104.

Ritchie K, Kildea D (1995) "Is senile dementia "age-related" or "ageing-related"? Evidence from meta-analysis of dementia prevalence in the oldest old" *Lancet* 346: 931-4.

Roorsman B, Hagnell O, Lanke J (1986) Prevalence and incidence of senile and multi-infarct dementia in the Lundby study: a comparison between the time periods 1947–1957 and 1957–1972. *Neuropsychobiology* 15:122-129.

Rosewarne R, Opie J, Ward S (2000) Dementia-specific care in Australia: an overview and future directions. *RPAD Vol 4: Special Care Units*.

Rosewarne R, Opie J, Bruce A, Ward S, Doyle C, Sach J (1997) Care Needs of People with Dementia and Challenging Behaviour Living in Residential Facilities. Aged and Community Care Service Development and Evaluation Reports Nos 24, 26-31, Commonwealth Department of Health and Family Services, AGPS, Canberra.

Shaji KS, Smitha K, Praveen Lal K, Prince M (2003) Care givers of patients with Alzheimer's disease : a qualitative study from the Indian 10/66 Dementia Research Network. *Int J Geriatr Psychiatry* 18:1–6.

Shaji S, Promodu K, Abraham T, Roy KJ, Verghese A (1996) An epidemiological study of dementia in a rural community in Kerala, India. *Br J Psychiatry* 168:745-749.

Schmidt R, Schmidt H, Curb JD et al (2002) Early inflammation and dementia: a 25-year follow-up of the Honolulu-Asia Aging Study. *Ann Neurol*. 52:168-174.

Sobel E, Dunn M, Davanipour Z, Qian Z, Chui H (1996) Elevated risk of Alzheimer's disease among workers with likely electromagnetic field exposure, *Neurology*, 47:1477-1481.

Sobel E, Davanipour Z, Sulkava R, Erkinjuntti T, Wikstrom J, Henderson V, Buckwalter G, Bowman J, Lee P-J (1995) Occupations with exposure to electromagnetic fields: a possible risk factor for Alzheimer's disease, *Am J Epidemiol*, 12:515-524.

Stern Y, Gurland B, Tatemichi T, Tang M, Wilder D, Mayeux R (1994) Influence of education and occupation in the incidence of Alzheimer's disease, *JAMA*, 271:1004-1010.

Sundstrom G (1992) Care by families: an overview of trends, in *Caring for Frail Elderly People*, Paris: OECD, 15-55.

United Nations (1994) The sex and age distribution of the world population: the 1994 revision. Department for Economic and Social Information and Policy Analysis Population Division: New York.



Wancata J, Musalek M, Alexandrowicz R, Krautgartner M (2003) "Number of dementia sufferers in Europe between the years 2000 and 2050" *Eur Psychiatry* 18:306-313.

Ward A , Caro JJ , Getsios D , Ishak K , O'Brien J , Bullock R (2003) Assessment of health economics in Alzheimer's disease (AHEAD): treatment with galantamine in the UK. *Int J Geriatr Psychiatry*. 18(8):740-7.

White L, Petrovitch H, Ross GW et al (1996) Prevalence of dementia in older Japanese-American men in Hawaii: The Honolulu-Asia Aging Study *JAMA* 276:955-960.

Wimo A, Jönsson L, Winblad B (2006a) An estimate of the worldwide prevalence and direct costs of dementia in 2003. *Dement Geriatr Cogn Disord* 21:175-181.

Wimo A, Jönsson L, Winblad B (2006b) The dementia worldwide costs database (DWCD).

Wimo A, Winblad B, Aguero-Torres H, vonStrauss E (2004) The magnitude of dementia occurrence in the world. *Alzheimer Dis Assoc Disord* 17:63–67.

Winblad B (2005) The Worldwide Costs of Dementia. Karolinska University Hospital, Huddinge and the Karolinska Institutet, Stockholm, Sweden, June.

World Health Organization (2006) Burden of disease estimates for 2002, available on http://www3.who.int/whosis/menu.cfm?path=evidence,burden,burden_estimates,burden_estimates_2002N,burden_estimates_2002N_2002Rev,burden_estimates_2002N_2002Rev_Region&language=english and projections from 2005, available on http://www3.who.int/whosis/menu.cfm?path=evidence,burden,burden_proj,burden_proj_results&language=english

World Health Organization (2003a) World Health Organization. World Health Report 2003—Shaping the future. Geneva: WHO, 2003.

World Health Organization (2003b) The Global Burden of Disease: A response to the need for comprehensive, consistent and comparable global information on diseases and injuries, *Epidemiology and Burden of Disease*, Geneva, available on http://www.who.int/mip/2003/other_documents/en/globalburdenofdisease.pdf

WHO (2001) *The world health report 2001 - Mental Health: New Understanding, New Hope*, Chapter 5 "The way forward" www.who.int/whr/2001/en/index.html

WHOQOL Group (1995) The World Health Organization Quality of Life Assessment (WHOQOL) position paper from the WHO. *Social Science and Medicine*, 41:1403- 9.

Zhang M, Katzman R, Salmon D et al (1990) The prevalence of dementia and Alzheimer's disease in Shanghai, China: Impact of age, gender, and education. *Annals of Neurology* 27:428-437.



APPENDIX: BRODATY TRIANGLE

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

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

Source: Brodaty et al (2003b). *Statistics based on clinical observations. ♣ Statistics based on Lyketsos et al (2000). BPSD = behavioural and psychological symptoms of dementia.



Dementia in the Asia Pacific Region:
The Epidemic is Here