



Alzheimer's Disease  
International

# World Alzheimer Report

2009

**Executive Summary**



**EMBARGOED FOR RELEASE UNTIL  
21 SEPTEMBER 2009**

## Preface

Demographic ageing is a worldwide process that shows the successes of improved health care over the last century. Many are now living longer and healthier lives and so the world population has a greater proportion of older people. We all agree that ageing brings some challenges as well. Many international meetings have touched on this issue and adopted statements, for instance the Madrid International Plan of Action on Ageing from 2002.

A clearly negative effect of ageing is the significant increase in the number of people with Alzheimer's disease and related dementias. Alzheimer's Disease International (ADI) has commissioned this report in order to support Alzheimer associations around the world in working with their governments on strategies to improve the lives of people with dementia and their carers, and to increase research efforts. To encourage the development of those national strategies, it is very important that the World Health Organization makes dementia a global health priority. If a country is in the business of supporting or spurring medical research, its portfolio ought to include funding Alzheimer's disease research in a proportion that matches its burden to the country.

To make clear why this is important and why it is urgent, we wanted to put together updated information on the prevalence and impact of the disease and offer a framework for solutions. Some recent experiences have been very encouraging. In 2004, Australia was the first country to make dementia a national health priority, and national dementia strategies have been launched in France, South Korea, England, Norway and the Netherlands. We also want to highlight a very recent initiative from the European Commission as the first international action plan on dementia.

This report gives an overview and analysis of the situation, based on the currently available research data. It is clear that more research on the prevalence and impact of the disease is needed. ADI will therefore carry out follow up reports, beginning with economic data in 2010. We hope this will stimulate all those involved: governments, policy makers, health care professionals and Alzheimer associations, to work together on more and better solutions for dementia. With a new case of dementia in the world every seven seconds there is no time to lose.

**Daisy Acosta**

Chairman  
Alzheimer's Disease International

**Marc Wortmann**

Executive Director  
Alzheimer's Disease International

### Editors

Martin Prince  
Jim Jackson

### Scientific Group

Cleusa P Ferri  
Renata Sousa  
Emiliano Albanese  
Wagner S Ribeiro  
Mina Honyashiki

Photos: Cathy Greenblat  
[www.cathygreenblat.com](http://www.cathygreenblat.com)  
Design: Julian Howell

### ADI Advocacy Working Group

Daisy Acosta (Dominican Republic)  
Marco Blom (Netherlands)  
Scott Dudgeon (Canada)  
Niles Frantz (USA)  
Angela Geiger (USA)  
Sabine Jansen (Germany)  
Andrew Ketteringham (UK)  
Lindsay Kinnaird (Scotland)  
Birgitta Martensson (Switzerland)  
Glenn Rees (Australia)  
Frank Schaper (Australia)  
Mike Splaine (USA)  
Tami Tamitegama (Sri Lanka)  
Krister Westerlund (Sweden)  
Marc Wortmann (ADI)

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 WORLD ALZHEIMER REPORT 2009  
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### Cover image

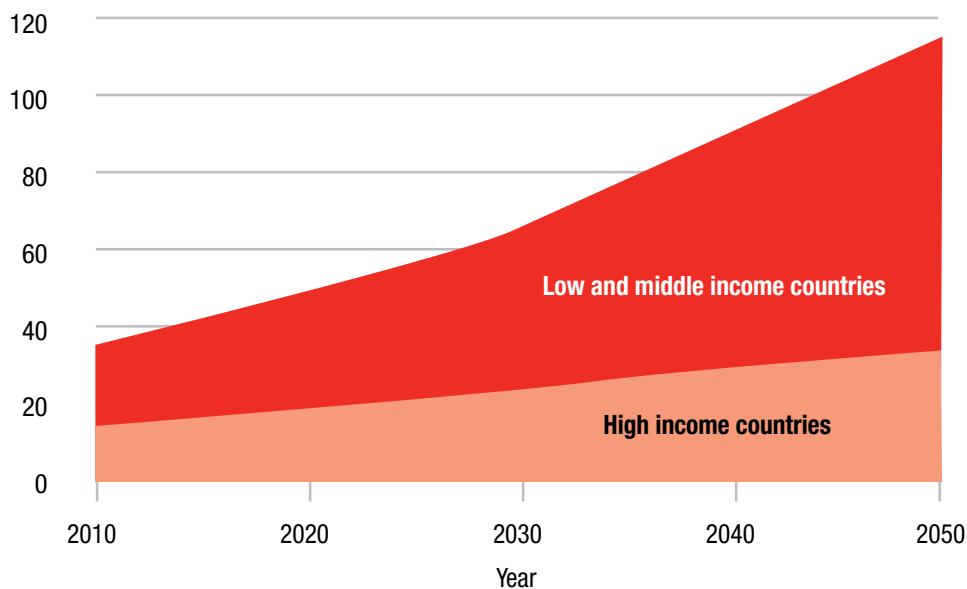
This participant in the ARDSI day care centre in Cochin, India, was diagnosed with dementia at age 68 and was initially taken care of at home by family and domestic servants. Her aggressive behaviour became problematic, and she was enrolled in the daycare centre. At the centre she chats, tells stories and benefits from trained staff members and volunteers, such as Geetha, who are understanding and kind.

## The growth of dementia

An estimated 35.6 million people worldwide will be living with dementia in 2010. This number is estimated to nearly double every 20 years, to 65.7 million in 2030, and 115.4 million in 2050. Much of the increase is clearly attributable to increases in the numbers of people with dementia in low and middle income countries.

Not only are the numbers reason for concern, but Alzheimer's disease and dementia have an enormous impact on societies; it can be called an epidemic that is increasing its pace with the 'graying' of the population around the world. Poor recognition, underdiagnosis and stigma cause significant problems for people with dementia and their families in countries of all sizes and communities of all income levels.

Figure 1 **The growth in numbers of people with dementia (in millions) in high income countries, and low and middle income countries**



### Alzheimer's Disease International

Alzheimer's Disease International (ADI) is the umbrella organisation of Alzheimer associations around the world. We aim to help establish and strengthen Alzheimer associations throughout the world, and to raise global awareness about Alzheimer's disease and all other causes of dementia.



## Recommendations

- 1 The World Health Organization (WHO) should declare dementia a world health priority.**
- 2 National governments should declare dementia a health priority and develop national strategies to provide services and support for people with dementia and their families.**
- 3 Low and medium income countries should create dementia strategies based first on enhancing primary healthcare and other community services.**
- 4 High income countries should develop national dementia action plans with designated resource allocations.**
- 5 Develop services that reflect the progressive nature of dementia.**
- 6 Distribute services with the core principle of maximising coverage and ensuring equity of access, to benefit people with dementia regardless of age, gender, wealth, disability, and rural or urban residence.**
- 7 Create collaboration between governments, people with dementia, their carers and their Alzheimer associations, and other relevant Non-Governmental Organisations and professional healthcare bodies.**
- 8 More research needs to be funded and conducted into the causes of Alzheimer's disease and other dementias, pharmacological and psychosocial treatments, the prevalence and impact of dementia, and the prevention of dementia.**



This photograph was taken on Mrs. Hagamima's 88th birthday. Her Alzheimer's disease did not prevent her from responding with great emotion to the singing of 'Happy Birthday'.

## Overview of the research

Alzheimer's disease and other dementias have been reliably identified in all countries, cultures and races in which systematic research has been carried out. However, levels of awareness vary enormously. Alzheimer's Disease International (ADI) has identified raising awareness of dementia among the general population and among health workers as a global priority<sup>(A11)</sup>.

In low and middle income countries, especially, there is a general lack of awareness of Alzheimer's and other dementias as medical conditions. Rather, they are perceived as a normal part of ageing<sup>(A9,12,13)</sup>. This general lack of awareness has important consequences.

- Affected individuals do not seek help from formal medical care services<sup>(A13)</sup>.
- There is little or no structured training on dementia recognition and management at any level of the health service.
- There is no constituency to place pressure on the government or policy makers to provide more responsive dementia care services<sup>(A9)</sup>.
- While families are the main caregivers, they must do so with little support or understanding from other individuals or agencies.

People with Alzheimer's and other dementias are often specifically excluded from residential care, where it exists, and often denied admission to hospital facilities<sup>(A13)</sup>. Disturbed behaviour, common among people with dementia, is particularly poorly understood, leading to stigma, blame and distress for caregivers<sup>(A14)</sup>.

The problem of low awareness is certainly not limited to low and middle income countries. For example, the National Dementia Strategy for the UK highlights stigma (preventing discussion of the problem) and two false beliefs (that dementia is a normal part of ageing and that nothing can be done) as the main factors linked to inactivity in seeking or offering help<sup>(A15)</sup>. In the UK, people typically wait three years before reporting symptoms of dementia to their doctor, 70% of caregivers report being unaware of the symptoms of dementia before diagnosis and 58% of caregivers believe the symptoms to be a normal part of ageing<sup>(A16)</sup>. Only 31% of primary care doctors believe that they have received sufficient training to diagnose and manage dementia<sup>(A17)</sup>.

The healthcare needs of older people have for too long been under-prioritised in global public health policy. This is now changing, due in part to the fact that demographic ageing (the 'graying' of the population) is proceeding more rapidly than first anticipated in all world regions, particularly China, India and Latin America<sup>(B2)</sup>. In the 30 years up to 2020, the oldest sector of the population will have increased by 200% in low and middle income countries as compared to 68% in the developed world<sup>(B3)</sup>. (See page 17 for definition of low, middle and high income countries.) With this increase, chronic non-communicable diseases assume a progressively greater significance in low and middle income countries. Chronic diseases are already the leading cause of death in all world regions apart from Sub-Saharan Africa<sup>(B5)</sup>.

In 2004, ADI convened a panel of international experts to review the global evidence on the prevalence of dementia and to estimate the prevalence of dementia in each world region, the current numbers of people affected, and the projected increases over time. The results were published in *The Lancet* in 2005. According to this article, in 2001, 24.2 million people lived with dementia worldwide, with 4.6 million new cases

developing annually<sup>(B6)</sup> (similar to the global incidence of non-fatal stroke)<sup>(B7)</sup>. Two-thirds of all people with dementia lived in low or middle income countries. Numbers were predicted to double every 20 years to more than 80 million by 2040, with much sharper increases in low and middle income than in high income countries.

However, a number of factors pointed to the need to update the prevalence estimates. The *Lancet*/ADI dementia prevalence baseline estimates were for 2001, with projections for 2020 and 2040. Given that prevalence data were lacking in many world regions, and inconsistent in others with few studies and widely varying estimates, these estimates were considered 'provisional'<sup>(B6)</sup>. There was a particular dearth of published epidemiological studies in Latin America<sup>(B20-22)</sup>, Africa<sup>(B10)</sup>, Russia, the Middle East and Indonesia. As a result, the consensus judgment of the international panel of experts was relied on in developing the estimates. Since the creation of the baseline estimates, dramatic, rapid growth worldwide in the older population has occurred; thus, greater numbers of older people are at risk for developing dementia.

In addition, the global evidence-base has expanded considerably. There have been new studies from Spain<sup>(B23,24)</sup>, Italy<sup>(B25)</sup> and the USA<sup>(B26)</sup>, as well as an explosion of studies from low and middle income countries and other regions and groups previously under-represented in the literature. These include ADI's 10/66 Dementia Research Group studies in Brazil, Cuba, Dominican Republic, Peru, Mexico, Venezuela, India and China<sup>(B13,27)</sup>, and new prevalence studies from Brazil<sup>(B28)</sup>, Peru<sup>(B29)</sup>, Cuba<sup>(B30)</sup>, Venezuela<sup>(B31)</sup>, China<sup>(B32)</sup>, Korea<sup>(B33)</sup>, India<sup>(B34)</sup>, Thailand<sup>(B35)</sup>, Australia (indigenous people)<sup>(B36)</sup>, Guam<sup>(B37)</sup>, Poland<sup>(B38)</sup> and Turkey<sup>(B39)</sup>. Further, the updating of the Global Burden of Disease (GBD) report by the World Health Organization (WHO) provides an impetus to revisit the literature and assess the extent to which it is possible (in some or all regions) to summarize the evidence on the prevalence of dementia by conducting meta-analyses of the available data, rather than relying on expert consensus.

The differences in approach between the earlier *Lancet*/ADI estimates and the new estimates derived for this report are summarized in Table 1.

Table 1 **Main differences in approach between *Lancet*/ADI estimates and current estimates**

	<i>Lancet</i> /ADI	Current review
<b>Search strategy</b>	Limited time and resources did not permit fully systematic review	Fully systematic review, with inclusion/exclusion criteria, specified search terms, multiple databases
<b>Regional subdivisions</b>	Estimates provided for 14 WHO world regions	Estimates provided for 21 WHO Global Burden of Disease world regions
<b>Method for generating regional estimates</b>	Regional estimates generated from expert Delphi consensus guided by all the available evidence	Regional estimates generated, where possible, from quantitative meta-analysis
<b>Stratification for prevalence estimates</b>	Age-specific prevalence in five year age bands to 85 and over	Age- and gender-specific prevalence in five year age bands to 90 and over
<b>Base year</b>	2001	2010
<b>Future projections</b>	2020/2040	2020/2030/2040/2050

## Methods

The methodology used is detailed in the full report and can be found online at [www.alz.co.uk/worldreport](http://www.alz.co.uk/worldreport). 135 publications describing 147 studies were used.

Table 2 provides a summary of the size of the elderly population by GBD Region and the numbers of the population studied.

## Results

The evidence-base was sufficient in terms of number and quality of studies, and coverage, to conduct meta-analyses for 11 of the 21 GBD regions: Western Europe, North America, Latin America (combining the Latin American Andean, Central, Southern and Tropical regions), Asia Pacific High Income, Australasia, East Asia, Southeast Asia and South Asia.

Estimated prevalence for all those aged 60 years and over, standardised to Western Europe, can be compared directly between the 21 GBD regions (Figure 2). There is a four-fold variation in prevalence overall, from 2.07% (Sub-Saharan Africa, West)

Table 2 **Coverage, by region, with respect to size of elderly population**

Region	Over 60 year old population (millions)	Number of eligible dementia prevalence studies	Number of studies/ 10 million population	Total population studied	Total population studied/ million population
<b>ASIA</b>	<b>406.6</b>	<b>73</b>	<b>1.7</b>	<b>193924</b>	<b>477</b>
Australasia	4.8	4	8.3	2223	462
Asia Pacific, High Income	46.6	22	4.7	31201	669
Asia, Central	7.2	0	0.0	0	0
Asia, East	171.6	34	2.0	142402	830
Asia, South	124.6	7	0.6	11905	96
Asia, Southeast	51.2	5	1.0	4164	81
Oceania	0.5	1	20.3	2029	4116
<b>EUROPE</b>	<b>160.2</b>	<b>61</b>	<b>3.8</b>	<b>80882</b>	<b>504</b>
Europe, Western	97.3	56	5.8	79043	813
Europe, Central	23.6	4	0.8	1839	78
Europe, Eastern	39.3	1	0.3	Not known	-
<b>THE AMERICAS</b>	<b>120.7</b>	<b>28</b>	<b>2.3</b>	<b>85053</b>	<b>705</b>
North America	63.7	13	2.0	38205	600
Caribbean	5.1	4	7.9	24425	4831
Latin America, Andean	4.5	3	6.7	3465	769
Latin America, Central	19.5	4	2.0	6344	325
Latin America, Southern	8.7	1	1.1	4689	537
Latin America, Tropical	19.2	3	1.6	5925	308
<b>AFRICA</b>	<b>71.2</b>	<b>5</b>	<b>0.7</b>	<b>6593</b>	<b>93</b>
North Africa / Middle East	31.1	2	0.6	3019	97
Sub-Saharan Africa, Central	3.9	0	0.0	0	0
Sub-Saharan Africa, East	16.0	0	0.0	0	0
Sub-Saharan Africa, Southern	4.7	1	2.1	150	32
Sub-Saharan Africa, West	15.3	2	1.3	3424	223

to 8.50% (Latin America). However, most of the estimated prevalence rates lie in a band between 5% and 7%. The major source of variation is clearly the very low estimated prevalence for the four Sub-Saharan Africa regions.

## Estimation of numbers of people with dementia

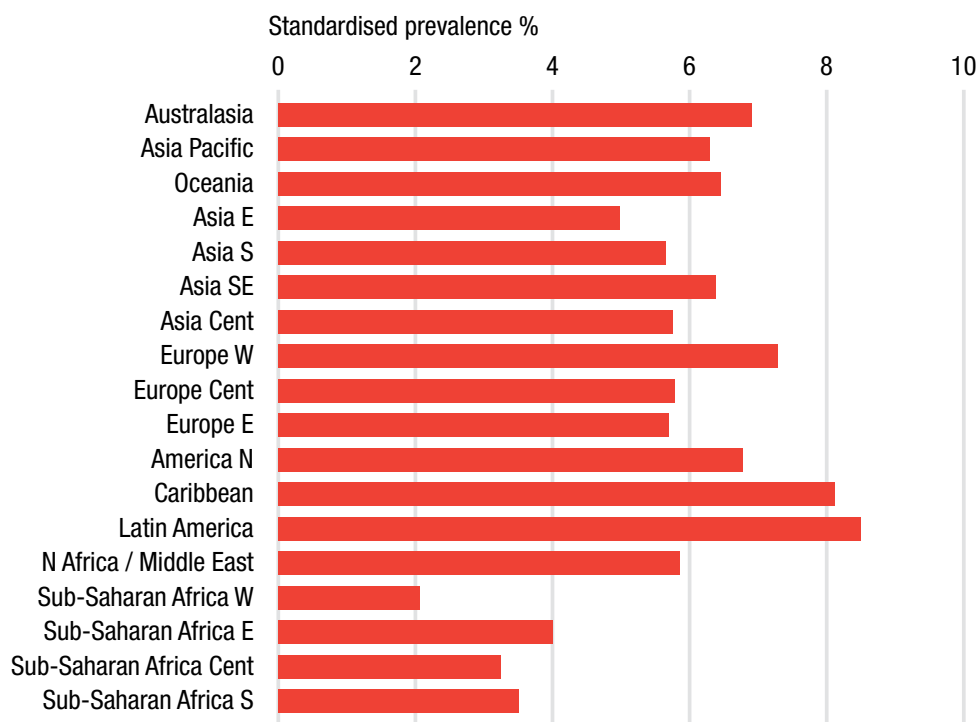
Having applied the age-specific, or age- and gender-specific prevalence estimates to United Nations population projections, an estimated 35.6 million people worldwide will be living with dementia in 2010. This number is estimated to nearly double every 20 years, to 65.7 million in 2030, and 115.4 million in 2050. Much of the increase is clearly attributable to increases in the numbers of people with dementia in low and middle income countries (Figure 1, page 2). In 2010, 57.7% of all people with dementia are expected to live in low and middle income countries, rising to 63.4% in 2030 and 70.5% in 2050.

The updated estimates for 2020 (48.1 million) and 2040 (90.3 million) can be compared directly with the earlier *Lancet*/ADI consensus estimates of 42.7 million for 2020 and 82.0 million for 2040. The new estimates are approximately 10% higher.

The earlier projections for growth in the number of people with dementia indicated that world regions fell into three broad groups:

- Developed regions started from a high base, and would experience a moderate proportionate increase.
- Latin America and Africa started from a low base, and would experience a particularly rapid increase in numbers.

Figure 2  
**Estimated prevalence of dementia for those aged 60 and over, standardised to Western Europe population, by GBD region**



- India, China, and their South Asian and Western Pacific neighbours started from a high base, and would also experience a relatively rapid growth.

A similar pattern is observed in the latest projections; these changes being driven mainly by population growth and demographic ageing. Over the next 20 years, the numbers of people with dementia are anticipated to increase by 40% in Europe, 63% in North America, 77% in the southern Latin American cone and 89% in the developed Asia Pacific countries. In comparison, the percentage increase is expected to be 117% in East Asia, 107% in South Asia, 134-146% in the rest of Latin America, and 125% in North Africa and the Middle East. See Table 3. ADI believes this report provides the best available estimates of prevalence and the numbers of people with dementia at a worldwide level, based on meta-analyses across many countries. ADI does not present estimates for individual countries and understands that different studies may be preferred to determine national figures.

**Table 3 Total population over 60, crude estimated prevalence of dementia (2010), estimated number of people with dementia (2010, 2030 and 2050) and proportionate increases (2010-2030 and 2010-2050) by GBD world region**

GBD Region	Over 60 population (millions)	Crude estimated prevalence (%)	Number of people with dementia (millions)			Proportionate increases (%)	
	2010	2010	2010	2030	2050	2010-2030	2010-2050
<b>ASIA</b>	<b>406.55</b>	<b>3.9</b>	<b>15.94</b>	<b>33.04</b>	<b>60.92</b>	<b>107</b>	<b>282</b>
Australasia	4.82	6.4	0.31	0.53	0.79	71	157
Asia Pacific	46.63	6.1	2.83	5.36	7.03	89	148
Oceania	0.49	4.0	0.02	0.04	0.10	100	400
Asia, Central	7.16	4.6	0.33	0.56	1.19	70	261
Asia, East	171.61	3.2	5.49	11.93	22.54	117	311
Asia, South	124.61	3.6	4.48	9.31	18.12	108	304
Asia, Southeast	51.22	4.8	2.48	5.30	11.13	114	349
<b>EUROPE</b>	<b>160.18</b>	<b>6.2</b>	<b>9.95</b>	<b>13.95</b>	<b>18.65</b>	<b>40</b>	<b>87</b>
Europe, Western	97.27	7.2	6.98	10.03	13.44	44	93
Europe, Central	23.61	4.7	1.10	1.57	2.10	43	91
Europe, East	39.30	4.8	1.87	2.36	3.10	26	66
<b>THE AMERICAS</b>	<b>120.74</b>	<b>6.5</b>	<b>7.82</b>	<b>14.78</b>	<b>27.08</b>	<b>89</b>	<b>246</b>
North America	63.67	6.9	4.38	7.13	11.01	63	151
Caribbean	5.06	6.5	0.33	0.62	1.04	88	215
Latin America, Andean	4.51	5.6	0.25	0.59	1.29	136	416
Latin America, Central	19.54	6.1	1.19	2.79	6.37	134	435
Latin America, Southern	8.74	7.0	0.61	1.08	1.83	77	200
Latin America, Tropical	19.23	5.5	1.05	2.58	5.54	146	428
<b>AFRICA</b>	<b>71.07</b>	<b>2.6</b>	<b>1.86</b>	<b>3.92</b>	<b>8.74</b>	<b>111</b>	<b>370</b>
North Africa / Middle East	31.11	3.7	1.15	2.59	6.19	125	438
Sub-Saharan Africa, Central	3.93	1.8	0.07	0.12	0.24	71	243
Sub-Saharan Africa, East	16.03	2.3	0.36	0.69	1.38	92	283
Sub-Saharan Africa, Southern	4.66	2.1	0.10	0.17	0.20	70	100
Sub-Saharan Africa, West	15.33	1.2	0.18	0.35	0.72	94	300
<b>WORLD</b>	<b>758.54</b>	<b>4.7</b>	<b>35.56</b>	<b>65.69</b>	<b>115.38</b>	<b>85</b>	<b>225</b>

## Relationships between Alzheimer's and other dementias and mortality and morbidity

A systematic review of the literature on cognitive impairment, dementia and mortality has reported a slightly higher relative risk of 2.63 for the effect of dementia and a dose response relationship between level of cognitive impairment and increasing mortality<sup>(C4)</sup>. The two studies of dementia and mortality carried out in low and middle income countries have both recorded somewhat larger effect sizes: 5.16 in Brazil<sup>(C5)</sup> and 2.83 in Nigeria<sup>(C6)</sup>.

According to the latest available GBD figures (for 2004) Alzheimer's and other dementias contribute 0.8% of all disability-adjusted life years (DALYs) worldwide, 1.6% of years lived with disability and 0.2% of years of life lost<sup>(C2)</sup>. Since dementia is mainly a disease of older people, the proportionate contribution is much greater among those aged 60 and over: 4.1% of DALYs, 11.3% of years lived with disability and 0.9% of years of life lost. A key finding from the GBD report is that chronic non-communicable diseases are rapidly becoming the dominant causes of ill-health in all developing regions except Sub-Saharan Africa<sup>(B5)</sup>.

The GBD report indicates that Alzheimer's and other dementias are main causes of disability in later life. Older people are particularly likely to have multiple chronic health conditions. These conditions interact in complex ways to create difficulties in performing important tasks and activities (disability) and in determining needs for care (dependence). Dementia has a disproportionate impact on capacity for independent living. In developed countries, where institutionalised long-term care is widely available, the onset of cognitive decline is often the precipitant for institutional placement, whereas people with quite severe disabilities arising from physical impairment continue to be supported at home by community services. As many as three-quarters or more of nursing home residents have dementia<sup>(C7)</sup>, and estimates of the proportion of all people with dementia who live in residential care homes vary between one-third<sup>(C7)</sup> and one-half<sup>(C10,11)</sup>.

There is an extensive literature from developed countries on the factors associated with institutionalisation among older people. In a comprehensive meta-analysis of 77 longitudinal community-based studies from the USA<sup>(C12)</sup>, cognitive impairment was by far the strongest health condition predictor of institutionalisation, increasing the risk two and a half fold. In comparison, the increased risks for



Good care in a group setting involves individualized care. The staff at the day care center in Cochin, India, understand the need to find activities that are meaningful to the participants given both their backgrounds and their present capabilities. This woman, a former mathematics teacher, likes to write numbers on paper or on the blackboard. The centre purchased the blackboard to help her feel connected to her past, experiencing old pleasures.

institutionalisation associated with cancer (1.15), hypertension (1.04) and diabetes (1.35) were modest, while no association was found between institutionalisation and cardiovascular disease, arthritis, or lung disease.

In low and middle income countries residential care is generally unavailable, and care is typically provided by family members at home.

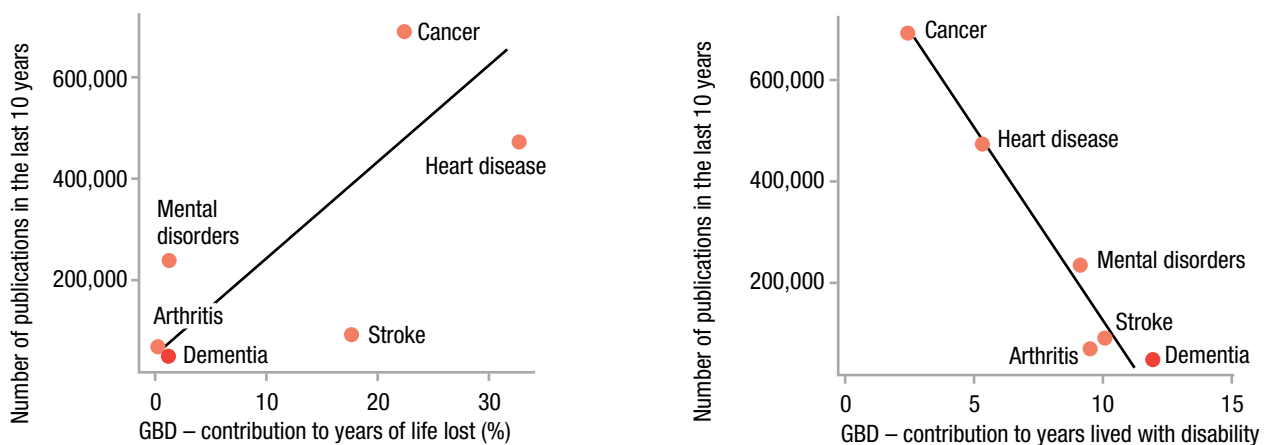
## Adding years to life and life to years

Different chronic diseases appear to have starkly different impacts on disability and mortality. Cardiovascular disease and cancer contribute much more to mortality than to disability<sup>(C2)</sup>. Successful interventions in these diseases can add years to life. The impact of dementia is felt much more through years lived with disability. Interventions might prevent or delay disability, adding 'life to years'. In practice, how do policymakers and practitioners decide how to allocate resources between these priorities?

Here is an example from one country: In the UK, much more is spent on healthcare for cardiovascular disease and cancer than on healthcare for dementia. The annual cost to the UK National Health Service (NHS) of treating coronary heart disease and hypertension has been estimated at £4.3bn (US\$6.9bn). A further £2.3bn (US\$3.7bn) is spent treating stroke (Institute of Actuaries). The cost of cancer care in the UK has been estimated at £2.1bn (US\$3.4bn)<sup>(C17)</sup>, but this figure is low compared to international norms; 10% of all healthcare expenditure in the UK compared with an estimated 40% in the USA<sup>(C17)</sup>. In the recent Dementia UK report the cost to the NHS of treating dementia was estimated to be just £1.4bn (US\$2.2bn)<sup>(C7)</sup>.

Another index of the priority accorded to different chronic diseases is the research effort that is contributed to each. In the USA, the National Institutes of Health report research expenditure in 2008 of \$5.6bn on cancer, \$2.3bn on cardiovascular disease and stroke, and \$0.4bn on dementia. Internationally, research effort can be readily assessed through Index Medicus listed research publications. A search of PubMed/Medline for the last 10 years identified 701,876 publications related to cancer, 476,487 related to heart disease, 233,872 related to mental disorders, 87,973 related to stroke, 64,080 related to arthritis and 44,168 related to dementia.

Figure 3 **Correlation of research effort (publications in last 10 years) with contributions to mortality (years of life lost) and disability (years lived with disability), for six major chronic diseases**



The correlation between research effort (number of publications), contribution to mortality (years of life lost) and contribution to disability (years lived with disability) is presented in Figure 3. Clearly, there is an inverse correlation between the contribution of these chronic diseases to years lived with disability and research effort. The more disabling the disease, the less it has been researched. Conversely, there is a strong positive correlation between years of life lost and research effort; the greater the disease contribution to mortality, the more it has been researched.

## The global cost of dementia

A research group from Sweden's Karolinska Institute has attempted to estimate the worldwide cost of dementia in 2005<sup>(C23,C40)</sup>. This amounts to US\$315 billion per year, of which US\$227 billion (72% of the worldwide total) is contributed by high income countries and US\$88 billion (28% of the total) by low and middle income countries. The estimated breakdown of these costs is illustrated in Figure 4. It can be seen that informal (family) care is more often used in resource-poor countries, where few formal health or social care services are available<sup>(C42)</sup>. Informal care accounts for 56% of costs in low income countries, 42% in middle income countries, and 31% in high income countries<sup>(C41)</sup>. Annual costs per person with dementia ranged from US\$1,521 for low income countries, to US\$4,588 in middle income countries, and US\$17,964 in high income countries.

Dementia care costs are rising fast in low and middle income countries<sup>(C23)</sup>. However, the absence of information about direct costs for Alzheimer's and other dementias is a major limitation in evaluating costs in low and middle income countries. However, the reasons attributed to the increasing costs that have been reported are:

- Rapid increases in numbers of people with dementia in those regions
- Substantial increases in average wages, used to calculate the opportunity cost or replacement cost of informal care
- Very high out-of-pocket healthcare costs reported from some middle income countries<sup>(C38)</sup>

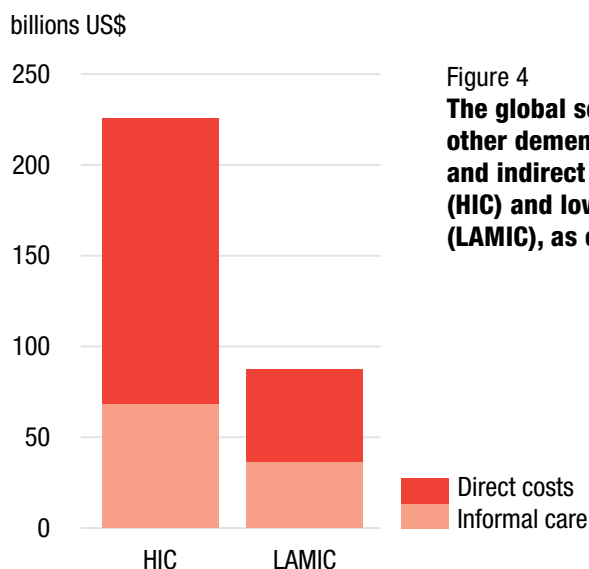


Figure 4  
**The global societal cost of Alzheimer's and other dementia in 2005, attributable to direct and indirect costs, in high income countries (HIC) and low and middle income countries (LAMIC), as estimated by Wimo et al<sup>(C23)</sup>**

Very little work has been done on evaluating the economic costs of dementia in low or middle income countries. There are several reasons for this, including a shortage of trained health economists, the low priority given to dementia, and the poorly developed state of services for people with dementia; however, the fundamental obstacle has been the absence of available data sets<sup>(C36)</sup>. Given that the needs of frail older people will soon come to dominate health and social care budgets in these regions, more data are urgently needed.

## Caregiving

All over the world, the family remains the cornerstone of care for older people who have lost the capacity for independent living. In developed countries, many of which have comprehensive health and social care systems, the role of families, and their need for support, is often overlooked. In developing countries, the reliability and universality of the family care system is often overestimated<sup>(C18,19)</sup>.

All people with dementia experience at least some degree of functional disability. This does not imply that they should all be regarded as needing care. Needs for care were assessed by the interviewer for all participants in the 10/66 Dementia Research Group's population-based studies in Latin America, India and China; needs for care among those with dementia (CDR 1 or above) are summarized in Figure 5. In most sites, between 50 and 70% of those with Alzheimer's and other dementias were rated as needing care, and most of those needing care needed 'much care'. Needs for care varied by level of dementia, with 30% of those with mild dementia, 69% of those with moderate dementia, and 88% of those with severe dementia needing much care.

The 10/66 Dementia Research Group's multicentre pilot study included 706 caregivers of people with Alzheimer's and other dementias in Latin America,

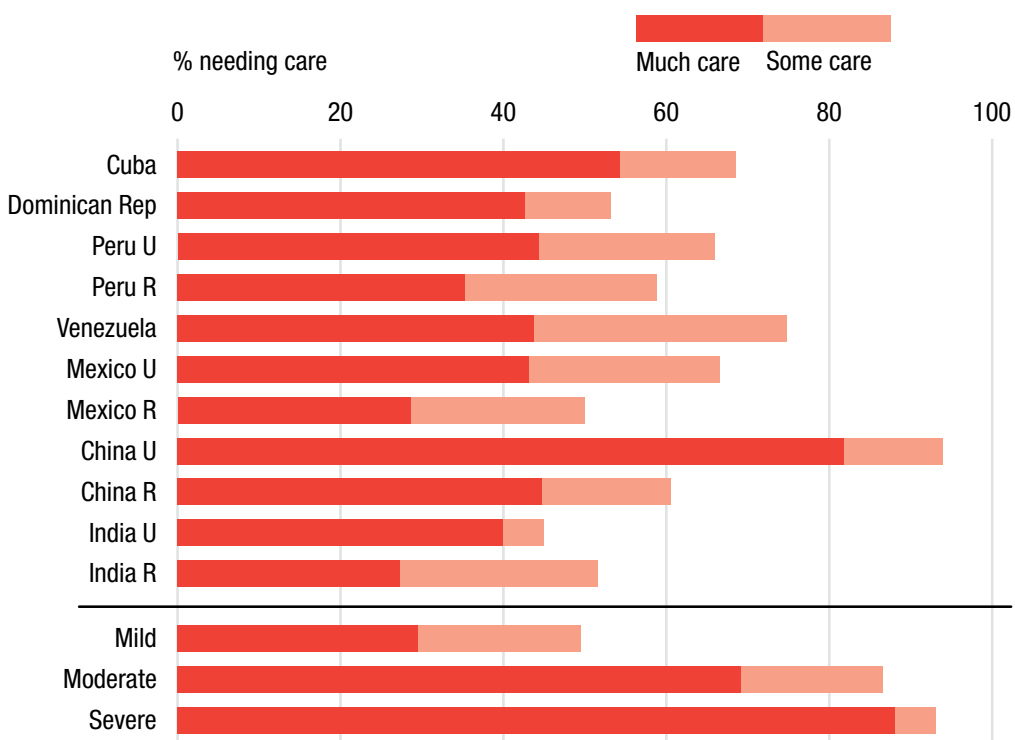


Daphne and her grandmother, Lara, visited Lara's mother, Margie, for the Thanksgiving celebration at a Silverado Senior Living Alzheimer's community in Houston, Texas. Daphne was saddened by Margie's loss of verbal communication skills. Lara convinced Daphne to tell her about the piano recital she would give the next day. After the connection was made, Margie signalled non-verbally that she had heard her great-granddaughter's story.

India and China<sup>(C21)</sup>. The EURO CARE study included 280 spouse caregivers from 14 European countries<sup>(C22)</sup>. In both studies, and across nearly all settings, most caregivers were women. In Europe, 85% or more of couples (one having Alzheimer's or another dementia, the other being their caregiver) lived on their own. In contrast, people with Alzheimer's or another dementia in the 10/66 pilot studies typically lived in large households, with extended families; one quarter to one half of households comprised three generations<sup>(C21)</sup>, including children under the age of 16 years. Living arrangements for people with dementia, and the characteristics of their caregivers were also assessed in the 10/66 Dementia Research Group's population-based studies, where 1345 people with dementia were studied in 11 sites in Latin America, China and India. Living alone or with a spouse only was very uncommon – the norm was to be living with adult children and/or children-in-law, often also with children under the age of 16. However, in urban China over a third of people with dementia lived with their spouse only. In all sites other than rural China, the overwhelming majority of caregivers were women, usually daughters or daughters-in-law caring for a parent. Only in China was the spouse quite commonly identified as the main caregiver.

A recent review of the literature<sup>(C23)</sup> identified 27 studies, overwhelmingly from high income countries, that provided information on time spent caring. Caregivers of people with Alzheimer's and other dementias spent an average of 1.6 hours daily assisting with core personal activities of daily living (including washing, dressing, grooming, toileting, eating). Including time spent assisting with instrumental activities of daily living (such as cooking, shopping, laundry, household finances) increased this figure to 3.7 hours, and when general supervision was also taken into account the average care input was 7.4 hours per day.

Figure 5  
**The prevalence of needs for care among people with dementia**  
**(10/66 Dementia Research Group population-based studies, data release 2.2)**  
 U = Urban R = Rural



## Consequences of caregiving

The negative consequences of caregiving have been widely studied. However, most family and friends who provide informal care take pride in their role, and perceive many positives. In Canada, 80% of a nationally representative sample of caregivers of people with dementia were able to identify positive aspects when asked to do so<sup>(C24)</sup>. These included companionship (23%), fulfilment (13%), enjoyment (13%), providing quality of life (6%) and meaningfulness (6%). Nevertheless, caregivers of people with dementia also experience high levels of strain, psychological morbidity and, possibly, impaired physical health.

In the USA, more than 40% of family and other unpaid caregivers of people with dementia rate the emotional stress of caregiving as high or very high. Interestingly, in low and middle income countries<sup>(C28)</sup>, while being part of a large household attenuated slightly the strain experienced by the main caregiver, traditional extended family care networks provided little protection; levels of caregiver strain were, in general, still as high as those seen in the European EURO CARE project<sup>(C22)</sup>.

Many studies have reported very high levels of psychological morbidity among caregivers of people with dementia, 40% to 75% in EURO CARE<sup>(C22)</sup>, with the same range of prevalence observed in 21 of the 24 10/66 pilot centres<sup>(C28)</sup>. A recent systematic review identified 10 studies that assessed the prevalence of major depressive disorder among caregivers of people with dementia using structured clinical interviews, which varied between 15 and 32%<sup>(C29)</sup>. In six of these studies the prevalence of major depression was compared with that in a control sample, with the prevalence in caregivers being 2.8 to 38.7 times higher.



Laughter and good moments are important for everyone, but are sometimes lacking for people with dementia. This carer in an Alzheimer's unit in Kyoto knew how to bring good humour, laughter, and an elevation of mood to the people he worked with.

## From recognition to action

In some countries, like Australia, France, South Korea and England, dementia is now a health priority and action plans have been launched. Key elements of these plans are to raise awareness among the general public and health professionals; improve diagnosis, treatment and services for long-term care; and increase the capacity of healthcare systems to respond to the challenge of the 'dementia epidemic'.

ADI has developed a seven-stage model for action for planning dementia services and a graduated approach for countries with limited resources. These are practical steps that all governments can take to improve the quality of life of people with dementia and their carers.

A graduated approach for low and medium income countries is illustrated in Figure 6. It focuses initial attention on awareness and understanding and from this, moves on to risk reduction and the underlying issues of capacity building and resource development. Service development starts in primary care before secondary care can be considered because it will be more equitable, benefiting more people with dementia and their families. It has the potential to prevent or at least delay the need for expensive institutional services that few families can afford. In countries where funding for health care is severely restricted, it is essential to start with initiatives that have the maximum impact for as many people as possible.

Figure 6 **A graduated approach to dementia service development**



Although awareness raising may appear to stand alone, in practice it should be considered in parallel to capacity building because when awareness is raised, expectations will also be raised that health and care services will be able to respond in some way. In enhancing the capacity of primary healthcare workers to provide the information, advice and training that will enable family carers to enhance their skills to care and so minimize the pressures on themselves, the first step is being taken to develop dementia services.

## Conclusions

The detailed estimates presented constitute the best currently available basis for policymaking, planning, as well as allocation of health and welfare resources.

In high income countries, the numbers of people with Alzheimer's or another dementia will continue to grow — particularly among the oldest old. The provision and financing of measures to meet the long term care needs of people with Alzheimer's or another dementia, including support for their family caregivers, is an increasingly urgent political priority. The health and social care needs of the large and rapidly growing numbers of frail dependent older people should also be a matter of great concern for policymakers in low and middle income countries.

These demographic changes and the growing impact of dementia make it imperative that governments take urgent action to improve dementia services in their own countries. Both the seven-stage model for planning dementia services and the graduated approach to dementia service development proposed by Alzheimer's Disease International provide frameworks to enable this to happen. By making dementia a world health priority, WHO would provide the leadership and encouragement for national governments to take the necessary action.

If government policies are well formulated and planned with the projections described in this report in mind, the inevitable shift of resource expenditure toward older people can be predicted and its consequences mitigated<sup>(B1)</sup>. If, as seems likely, early and late life patterns of morbidity and mortality converge with those of the developed west, prevalence rates for Alzheimer's and other dementia will do likewise. Further, given the assumption of the prevalence rate remaining constant, the implications for the rates of growth in the numbers of people with Alzheimer's and other dementias in developing regions may be significantly underestimated.

Efforts to improve the quality and availability of care, as well as efforts to find more effective treatments for Alzheimer's and other dementias, should be coupled with urgent investment in primary disease prevention measures. More research is required to identify modifiable risk factors for Alzheimer's and other dementia. In the meantime, primary prevention should focus upon targets suggested by current evidence: risk factors for vascular disease, including hypertension, smoking, type II diabetes and hyperlipidemia.

## Future directions

Efforts need to be made in all global regions to monitor trends in incidence and prevalence rates of Alzheimer's and other dementias. The estimates will now be updated regularly in future reports issued by the ADI. The current evidence base provides a strong baseline. A clearer picture of global incidence and prevalence of Alzheimer's and other dementias will emerge as more evidence accumulates from currently underrepresented regions.

## Documentation

In the interests of transparency and international scientific collaboration, all of the documentation for this review is made available at [www.alz.co.uk/worldreport](http://www.alz.co.uk/worldreport), including the data file with extracted study characteristics and prevalence data.

The full 2009 World Alzheimer's Report with supporting materials – of which this is a condensed version – can also be found at [www.alz.co.uk/worldreport](http://www.alz.co.uk/worldreport).

## Definition of low, middle and high income countries

The World Bank's main criterion for classifying economies is the gross national income (GNI) per capita. It was previously referred to as gross national product (GNP).

- **Geographic regions:** Classifications and data reported for geographic regions are for low-income and middle-income economies only. Low-income and middle-income economies are sometimes referred to as developing economies. Classification by income does not necessarily reflect development status.
- **Income group:** Economies are divided according to 2008 GNI per capita into the following groups. The income classifications are set each year on 1 July.
  - Low income: \$975 or less
  - Lower middle income: \$876-\$3,855
  - Upper middle income: \$3,856-\$11,905
  - High income: \$11,906 or more

Global Burden of Disease Regions included in meta-analyses: (see page 6)

- Asia
  - Australasia
  - Asia Pacific, High Income
  - Asia, East
  - Asia, South
  - Asia, Southeast
- Europe
  - Europe, Western
- The Americas
  - North America
  - Latin America (four regions)



Jacqueline in a reminiscence therapy session, 2008, Nice, France. Reminiscence therapy is based on the evocation of older memories and autobiographies. The sharing of these memories, sometimes with the aid of photographs and other objects, in a group helps to promote social exchanges, and through this communication the quality of life of people with dementia and family carers is improved.

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For consistency, we have retained the reference numbers from the full version of the World Alzheimer Report 2009 with a prefix to indicate the chapter. They are listed here in the order that they are cited in this Executive Summary.

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Len and Bette have been married for 63 years. He cared for her at home in Ohio, USA, for the first years of her cognitive difficulties, until her wandering and other problems led both the doctor and their children to urge an institutional placement. Len is consumed by her losses and his losses. 'I've left everything in the house the way it used to be as if she might come home. But in the long run I know it's not true. I've lost her. She's here but I've lost her. I'd give you my bronze star if you could bring her back.'

Alzheimer's Disease  
International: The International  
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not-for-profit organization

Alzheimer's Disease International  
64 Great Suffolk Street  
London SE1 0BL  
UK  
Tel: +44 20 79810880  
Fax: +44 20 79282357  
[www.alz.co.uk](http://www.alz.co.uk)



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