



**Alzheimer's Disease  
International**

*The global voice on dementia*

# Dementia in the Asia Pacific Region



## **Dementia in the Asia Pacific Region**

### **Authors**

Alzheimer's Disease International

Alzheimer's Australia

Published by Alzheimer's Disease International, London, November 2014

Copyright © Alzheimer's Disease International

### **Acknowledgements**

Annexes – the member associations of ADI in the Asia Pacific region

Dr Matthew Prina, Global Observatory for Ageing and Dementia Care, King's College London, UK  
– assistance with prevalence data from the 10/66 Dementia Research Group

Prof Anders Wimo, Karolinska Institutet, Stockholm, Sweden – assistance with the cost data

Photos for cover, chapters 1, 2, 3 and 5 – iStock

Photo for chapter 4 – Alzheimer's Disease Association (Singapore)

Photo for chapter 6 – Alzheimer's and Related Disorders Society of India

Design – David O'Connor – [www.daviddesigns.co.uk](http://www.daviddesigns.co.uk)

# Foreword

The purpose of this document is to promote a greater understanding and awareness of the social and economic impact of Alzheimer's disease and other dementias across the countries of the Asia Pacific region. These impacts will be felt not only by health and care systems, but by the families and friends who support the 71 million people with dementia that there will be in the Asia Pacific by the middle of this century.

This publication sets out information on dementia as well as the facts and figures on the prevalence of dementia in the member countries of Alzheimer's Disease International in the Asia Pacific. This document, like its predecessor in 2006, will provide a basis for dialogue and discussion with governments that promote a better understanding of the consequences of dementia for health and care systems and what is needed to better support the family and friends of people with dementia in the community.

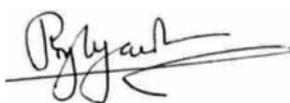
The capacity of different countries to respond to the economic and social issues raised by dementia will of necessity vary by their economic status. Nonetheless this publication sets out to illustrate that whether the level of resources available to governments is low or high, there are strategies that can be adopted in ensuring that those living with dementia have a better quality of life.

The fundamental needs at this time are for a better understanding of dementia and its social and economic impacts, and for strategies that better support families and those in the community. The strategies appropriate to different countries will vary according to their cultural values but fundamental is the timely diagnosis of dementia and provision of information and community support.

The mission of Alzheimer's Disease International (ADI) is to ensure that its 18 member associations in the Asia Pacific region are supported in their advocacy at international and national levels and to help establish Alzheimer associations in those countries that currently have no such organisation. Through the ADI Asia Pacific Office the objective is to provide education and support activities that will help individual countries better inform and train their health workers and communities on dementia.



**Marc Wortmann**  
Executive Director  
Alzheimer's Disease  
International



**Dr Jacob Roy Kuriakose**  
Chairman  
Alzheimer's Disease  
International



**Glenn Rees**  
Chair Elect  
Alzheimer's Disease  
International

7th November 2014

# Contents

## CHAPTER 1

### **Executive summary** 3

## CHAPTER 2

### **About dementia** 6

What is dementia? 6

Types of dementia 6

Diagnosis and treatment 7

Risk factors of dementia 7

Disease burden 7

## CHAPTER 3

### **Prevalence and costs of dementia** 9

Prevalence in the Asia Pacific region 9

Economic cost 10

## CHAPTER 4

### **Strategies to address the dementia epidemic** 12

Dementia pathways 12

Strategies for the care of people with dementia 14

Strategies to address dementia by country 16

ADI member organisation profiles and environment 16

## CHAPTER 5

### **Risk reduction** 18

The evidence 18

The potential for prevention 18

Links with other diseases and their effective management 19

## CHAPTER 6

### **Conclusions and recommendations** 20

## ANNEXES

### **Country profiles** 21

Australia 21

Bangladesh 24

China, People's Republic of 27

China, Hong Kong, SAR 29

China, Macau, SAR 31

India 34

Indonesia 36

Japan 37

Korea 40

Malaysia 42

Nepal 44

New Zealand 46

Pakistan 49

Philippines 51

Singapore 53

Sri Lanka 55

TADA, Chinese Taipei 58

Thailand 60

## CHAPTER 1

## Executive summary



In 2006, the first report on *Dementia in the Asia Pacific* was published. Since then, there have been a number of developments in the region, including country-specific initiatives by governments and Alzheimer associations, as well as the availability of updated data. In addition, Alzheimer's Disease International (ADI) has increased its membership in the region from 15 to 18 members and, in 2013, established the Asia Pacific Regional Office (APRO) to intensify its efforts to support and strengthen member associations in the region. The APRO is based in Singapore.

In December 2013, the member associations at the Asia Pacific Regional Meeting in Hong Kong SAR agreed to commission an updated report for the following reasons:

1. To provide updates for governments/Health Ministries in the region
2. To raise awareness through mainstream and social media to remove the stigma of dementia
3. To increase the knowledge of strategies for dementia care and risk reduction for those interested in the cause

This report:

- Describes dementia and the impact of the disease
- Provides updated prevalence and cost information for each country in the region

- Offers insights for each of the ADI member associations in the region and environment in which they operate
- Suggests an integrated care pathway concept in relation to the journey of a person with dementia
- Provides information on strategies for dementia care based on an updated framework of the ADI-Kyoto Declaration of 2004
- Provides evidence on risk reduction activities to help delay the onset of dementia

This report also combines the ADI World Alzheimer's Month themes of the Journey of Caring (2013) and Risk Reduction (2014).

### The facts

The 18 member associations of ADI in the Asia Pacific region are located in Australia, Bangladesh, China, Chinese Taipei, Hong Kong SAR, India, Indonesia, Japan, Macau SAR, Malaysia, Nepal, New Zealand, Pakistan, Philippines, Singapore, Republic of Korea, Sri Lanka and Thailand.

The population of the Asia Pacific region in 2015 is estimated at 4 billion based on ADI's categorisation of regions. Accordingly, estimates show that more than 11% of the population in the region is over 60 years of age<sup>1,2</sup>. It is expected that by 2050 a quarter of the total population in the Asia Pacific region will be aged 60 years or older.

Table 1.1  
**Estimated costs and number of people with dementia in the Asia Pacific region**

	Projected Population ('000) <sup>+</sup>	Estimated Number of people with Dementia ('000)			Estimated Costs US\$ (mil)
	Y2015	Y2015	Y2030	Y2050	2015
<b>ADI Members</b>					
Australia	23,923	328	520	864	\$ 12,892
Bangladesh	160,411	460	834	2,193	\$ 321
China, P.R.	1,401,587	10,590	18,116	32,184	\$ 44,619
China, Hong Kong SAR	7,314	115	212	436	\$ 3,227
China, Macau SAR	584	4	11	26	\$ 158
Chinese Taipei	23,380	260	461	840	\$ 6,990
India	1,282,390	4,031	6,743	12,542	\$ 4,620
Indonesia	255,709	1,033	1,894	3,979	\$ 1,777
Japan	126,818	3,014	4,421	5,214	\$ 93,240
Malaysia	30,651	123	261	590	\$ 705
Nepal	28,441	78	134	285	\$ 52
New Zealand	4,596	60	96	154	\$ 1,199
Pakistan	188,144	450	712	1,422	\$ 642
Philippines	101,803	301	568	1,149	\$ 599
Singapore	5,619	45	103	241	\$ 1,664
Republic of Korea	49,750	462	974	2,113	\$ 8,676
Sri Lanka	21,612	147	262	463	\$ 230
Thailand	67,401	600	1117	2,077	\$ 1,810
<b>ADI members total</b>	<b>3,780,133</b>	<b>22,100</b>	<b>37,438</b>	<b>66,772</b>	<b>\$ 183,422</b>
<b>Non ADI members*</b>	211,660	1,179	1,970	4,209	\$ 1,446
<b>Total Asia Pacific</b>	<b>3,991,793</b>	<b>23,279</b>	<b>39,409</b>	<b>70,981</b>	<b>\$ 184,868</b>

+ Population projection from ADI based on UN data (<http://esa.un.org/wpp/>)

\* Non ADI members consists of 21 countries/territories

Prevalence and cost data from ADI's World Alzheimer Report 2009, World Alzheimer Report 2010 and G8 policy brief 2013. As the prevalence rates and the number of people with dementia are derived from projected population figures, some data may vary from different reports and analyses.

The increase in ageing also extends to the oldest-old or those aged 80 and over. The proportion of the oldest-old in the Asia Pacific region has increased dramatically; in 1990, the proportion of those aged 80 years and over was 0.8% which rose to 1.4% in 2012 with projections indicating this will increase to 4.4% by 2050.

Globally, the number of people with dementia in 2013 was estimated at 44 million people, rising to 76 million in 2030 and 135 million in 2050. In the Asia Pacific region, the number of people with dementia is estimated to

increase from 23 million people in 2015 to 71 million people by the year 2050.

The worldwide costs associated with dementia are tremendous with estimates indicating that in 2010 US\$604 billion was spent on the disease. These costs related to informal care (such as unpaid family carers), social care (community and residential care) and medical care (treatments in primary and secondary care)<sup>3</sup>.

For the Asia Pacific region, costs associated with dementia have been estimated at US\$185 billion. Based

on the 2015 data, around 70% of the total costs of dementia care were from the advanced economies, which contain 18% of the prevalence.

The costs associated with caring for a person with dementia differ radically between countries and are dependent upon such factors as urbanisation, cultural and family structures, public health infrastructure, care services, gross domestic product, and government. Those countries with a low or middle income invariably have larger costs associated with informal care for the person with dementia whilst care costs in high income countries are relatively evenly distributed across informal and social care<sup>4</sup>.

## The challenge

The Asia Pacific Region faces specific challenges relating to dementia including:

- Limited awareness of dementia and in many countries a cultural context that denies its existence or attaches stigma to dementia
- An assumption that dementia is a natural part of ageing and not a result of a disease
- Inadequate human and financial resources to meet the care needs of people with dementia and limited policy on dementia
- Inadequate training for professional carers and lack of support for family carers

## Recommendations

The Asia Pacific countries already have around half of the world's population. The number of people living with dementia in the Asia Pacific region will triple between now and 2050. There is an urgent need for governments to put in place policies and plans to ensure that adequate care and services are provided to people living with dementia in the future.

The updated 2004 Kyoto Declaration provides a framework for action for governments, non-government organisations and other stakeholders in the Asia Pacific region. Here are the recommendations:

- 1 Provide education and awareness about Alzheimer's disease and other dementias, highlighting that dementia is not a normal part of ageing but a disease of the brain.
- 2 Improve the quality of life of people living with dementia by providing education to family members, paid carers and other health care professionals to ensure that the best quality of care is delivered to people living with dementia.
- 3 Promote the development of health and community care systems to deal with an increasing number of people with the disease. To the extent possible ensure that health and community care systems are adequately equipped to provide care and treatment,

provide education or professional development to family, paid carers and health care workers, and adequately and continuously invest in health and community care systems.

- 4 Raise awareness of prevention and risk reduction strategies which may delay the onset of the disease for some individuals and reduce future numbers of people with dementia.
- 5 Countries to develop national dementia action plans detailing key areas for action including research, awareness and education, improving quality of care, prevention and risk reduction and assessment and diagnosis. The Kyoto Declaration provides a framework of possible strategies for countries to consider.
- 6 Promote and support further research into the health and care systems in lower and middle income countries in the development of health policy.

## References

1. United Nations ESCAP. Population Trends in Asia and the Pacific. Nov 2013 <http://www.unescapsdd.org/files/documents/SPPS-Fact-sheet-Population-Trends-v3.pdf>
2. World Health Organization. Global Health Observatory website dated 21 April 2014. <http://apps.who.int/gho/data/node.country>.
3. Alzheimer's Disease International. World Alzheimer Report 2010: The Global Economic Impact of Dementia. <http://www.alz.co.uk/research/world-report-2010>
4. World Health Organization. (2012). Dementia: a public health priority [http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1)

## CHAPTER 2

## About dementia



### What is dementia?

Dementia is a syndrome that results in the progressive deterioration of cortical functioning including language, judgment, comprehension, memory, thinking and learning<sup>1</sup>. The course of dementia will vary from person to person and is related to a range of factors including the subtype of dementia, physical health, lifestyle factors and the social supports of the person with the disease<sup>2,3,4</sup>. As dementia advances, the person's ability to carry out activities of daily living such as shopping or managing finances will decline, eventually resulting in the person needing assistance to undertake even simple activities<sup>2,3</sup>.

### Types of dementia

Dementia is caused by a variety of diseases with some of the most common being:

**Alzheimer's disease** is the most common cause of dementia accounting for between 50-75% of dementia cases<sup>5,6,7</sup>. Alzheimer's disease is characterised by changes in the brain due to a build-up of abnormal plaques and tangles. Alzheimer's disease can be either **sporadic** or **familial**<sup>7</sup>. **Sporadic** Alzheimer's disease can affect adults at any age, but usually occurs after age 65 and is the most common form of Alzheimer's disease<sup>7</sup>. **Familial** Alzheimer's disease is a very rare genetic condition, caused by a mutation in one of several genes<sup>7</sup>. The presence of mutated genes means that the person will eventually develop Alzheimer's disease, usually in

their 40's or 50's<sup>8</sup>. The rate of progression will vary from person to person but will eventually lead to complete dependence and finally death, usually from another illness such as pneumonia. A person may live from three to twenty years with Alzheimer's disease, with the average being seven to ten years<sup>7</sup>.

**Vascular dementia** is the second most common cause of dementia in between 20-30% of cases and is as a result of decreased blood flow to the brain which deprives brain cells of essential nutrients and oxygen<sup>5,6,9</sup>. Multi-infarct dementia is caused by a number of small strokes, called mini-strokes or Transient Ischaemic Attacks (TIA) which cause damage to critical regions of the brain<sup>10</sup>.

**Vascular dementia** usually progresses gradually in a step-wise fashion in which a person's abilities deteriorate after a stroke, and then stabilise until the next stroke. If further strokes do not occur, the abilities of people with vascular dementia may not continue to decline, or in some cases, may improve. However, these improvements may not last. Sometimes the steps are so small that the decline appears gradual. On average though, people with vascular dementia decline more rapidly than people with Alzheimer's disease. Often they die from a heart attack or major stroke<sup>10</sup>.

**Frontotemporal dementia** accounts for around 5-10% of dementia cases. No single pathology has been identified with the disease caused by the degeneration of

cells in the brain's frontal or temporal lobes<sup>5,6</sup>. Although frontotemporal dementia can affect people at any age, it usually begins between 40 and 65 years of age and is a significant cause of dementia in younger people. Pick's disease is a type of frontotemporal dementia named after the German neurologist who first described it in 1892<sup>11</sup>. Pick's disease affects the frontal lobes, but in some cases can affect the temporal lobe of the brain. If the temporal lobe is damaged, memory is more likely to be affected. From the onset of the disease, life expectancy is two to fifteen years, with an average of six to twelve years. Death usually comes from another illness such as an infection<sup>11</sup>.

**Dementia with Lewy bodies** accounts for less than 5% of dementia cases<sup>5,6</sup>. Lewy body disease is caused by the degeneration and death of nerve cells in the brain. The name comes from the presence of abnormal spherical structures called Lewy bodies, which develop inside nerve cells. It is thought that these may contribute to the death of the brain cells<sup>12</sup>. Lewy body disease differs from Alzheimer's disease in that the progression of the disease is usually more rapid. However, like Alzheimer's disease it is a degenerative condition, eventually leading to complete dependence. Death is usually a result of another illness, such as pneumonia or an infection. The average lifespan after the onset of symptoms is about seven years<sup>12</sup>.

**Younger onset dementia** (also referred to as early onset dementia) is the term used to describe any form of dementia diagnosed in people under the age of 65. Few studies into the prevalence of younger onset dementia have been conducted globally, often because epidemiological studies of dementia frequently exclude people under the ages of 65 or 60<sup>5</sup>.

In Australia, an epidemiological study surveyed a wider range of clinicians and services and identified 142 younger onset dementia cases using DSM-IV (Diagnostic and Statistical Manual of Mental Disorders -IV) dementia criteria. The prevalence rate was 67.4/100,000 (95% CI 55.5-73.9) in people aged 30 to 64 years. The primary sub-types identified differed: alcohol related dementia was the most common sub-type (22%), followed by Alzheimer's disease (16%), Frontotemporal dementia (13%) and Vascular dementia (10%)<sup>13,5</sup>.

The needs of a person with younger onset dementia will differ from older people and extra consideration is necessary as the dementia appears at an earlier stage of their life when they are likely to be more physically and socially active. When diagnosed, a person with younger onset dementia may be in full time employment, actively raising a family, financially responsible for the family and physically strong and healthy. When considering the policy implications of those living with younger onset dementia, it is important to note that eligibility for social/medical supports and old age pensions are commonly based on meeting specific age requirements which younger people would not meet<sup>14</sup>.

**Other dementias** include Korsakoff Syndrome, traumatic brain injury, Parkinson's disease, Huntington's disease, HIV dementia and mixed dementia.

## Diagnosis and treatment

Even in higher income countries, perhaps only 50% of those with dementia receive a diagnosis and that there are significant issues in respect of achieving a timely diagnosis<sup>16</sup>. A diagnosis of dementia in higher income countries is generally given after a comprehensive assessment is conducted, including reviewing the individual's medical history, a physical examination and the use of cognitive screening tools<sup>3,5</sup>. Interviews with carers or family members also provide the clinician with invaluable information regarding the individual's cognitive functioning<sup>15</sup>. In lower and middle-income countries, many fewer people are diagnosed, probably less than 10% of those living with the disease<sup>16</sup>.

Currently, there are no treatments available that cure, or even alter the progressive course of dementia, although numerous new therapies are being investigated in various stages of clinical trials<sup>17</sup>. Partially effective treatments are available for most core symptoms of dementia. These treatments are all symptomatic, that is they can improve a particular symptom, but do not alter the progressive course of the disease. Importantly, psychological and psychosocial therapies (sometimes referred to as 'non-pharmacological interventions') may be as effective as drugs in many areas, but have been less extensively researched, and much less effectively promoted<sup>2</sup>.

## Risk factors for dementia

There are number of risk factors associated with dementia with many of these factors acting in conjunction to increase the person's overall risk of developing dementia<sup>3,5</sup>. Risk factors including age, family history, stroke, diabetes, obesity, high cholesterol, hypertension and physical inactivity all share an association with dementia. The risk factors for dementia are discussed in further detail in Chapter 5 – Risk Reduction.

## Disease burden

In 2012, the World Health Organization released the report, *Dementia: a public health priority*<sup>14</sup>. Key messages from the report revealed the increasing number of people living with dementia. There are over 7.7 million new cases of dementia each year, suggesting that there is a new case of dementia somewhere in the world every four seconds.

**Mortality:** mortality estimates for dementia are difficult to assess<sup>14</sup>. Death certificates are frequently unreliable, largely due to the fact that dementia is rarely considered as a direct or underlying cause of death. People with dementia often have additional co-occurring health conditions that may or may not be related to the dementia process and which themselves may hasten

death. In 2012, *The Lancet* reported results from the Global Burden of Disease (GBD) study, finding that deaths from dementia in 2010 rose threefold over 1990. When looking at age standardised rates of mortality, Alzheimer's disease had a 95.4% increase in rates of death per 100,000 population over that same period of time<sup>18</sup>.

**Disability:** Dementia and cognitive impairment are leading causes of disability amongst older people worldwide<sup>19</sup>. In 2010, 101 million or 29% of the people worldwide who required care were older adults aged 60 years and over<sup>19</sup>. By 2050, the number of people requiring care aged 60 years and over is expected to increase to 277 million, or 45% of the total population<sup>19</sup>.

## References

1. World Health Organization. (2006). Neurological disorders: public health challenges. [http://www.who.int/mental\\_health/neurology/neurodiso/en/](http://www.who.int/mental_health/neurology/neurodiso/en/)
2. Alzheimer's Disease International. World Alzheimer Report 2009 Prevalence and overview. <http://www.alz.co.uk/research/world-report-2009>
3. Australian Institute of Health and Welfare. (2012). Australia's Health 2012. <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737422169>
4. Lipton, A. M. & Marshall, C. D. (2012). The common sense guide to dementia for clinicians and caregivers. New York: Springer.
5. Seeher, K., Withall, A. & Brodaty, H. (eds.) (2011). The dementia research mapping project - the 2010 update: final report. Sydney: Dementia Collaborative Research Centre, University of New South Wales.
6. Draper, B. (2011). Understanding Alzheimer's & other dementias. Woollahra: Longueville Books
7. Alzheimer's Australia. (2012). Alzheimer's Disease. [http://www.fightdementia.org.au/common/files/NAT/2012\\_NAT\\_HS\\_AD\\_13\\_AD.pdf](http://www.fightdementia.org.au/common/files/NAT/2012_NAT_HS_AD_13_AD.pdf)
8. Alzheimer's Association. (2014). The Search for Alzheimer's Causes and Risk Factors. [http://www.alz.org/research/science/alzheimers\\_disease\\_causes.asp](http://www.alz.org/research/science/alzheimers_disease_causes.asp)
9. Alzheimer's Association. (2014). Vascular Dementia. <http://www.alz.org/dementia/vascular-dementia-symptoms.asp>
10. Alzheimer's Australia. (2012). Vascular Dementia. [http://www.fightdementia.org.au/common/files/NAT/2012\\_NAT\\_HS\\_AD\\_16\\_VascularDementia.pdf](http://www.fightdementia.org.au/common/files/NAT/2012_NAT_HS_AD_16_VascularDementia.pdf)
11. Alzheimer's Australia. (2012). Fronto Temporal Lobar Degeneration. <http://www.fightdementia.org.au/understanding-dementia/fronto-temporal-lobar-degeneration.aspx>
12. Alzheimer's Australia. (2012). Lewy Body Disease. [http://www.fightdementia.org.au/common/files/NAT/2012\\_NAT\\_HS\\_AD\\_20\\_LewyBody.pdf](http://www.fightdementia.org.au/common/files/NAT/2012_NAT_HS_AD_20_LewyBody.pdf)
13. Withall, A. & Draper, B. (2009). What is the burden of younger onset dementia in Australia? *International Psychogeriatrics*, 21(SupplementS2): S26-7.
14. World Health Organization. (2012). Dementia: a public health priority. [http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1)
15. O'Connor. (2005). Epidemiology. In D. Ames, A. Burns & J O'Brien (eds). *Dementia 3<sup>rd</sup> edition*. Florida: Taylor & Francis Group.
16. Alzheimer's Disease International. World Alzheimer Report 2011: The benefits of early diagnosis and intervention. <http://www.alz.co.uk/research/world-report-2011>
17. World Health Organisation. (2012). Dementia Fact Sheet No 362 <http://www.who.int/mediacentre/factsheets/fs362/en/>
18. Alzheimer's Disease International. World Alzheimer Report 2012: Overcoming the stigma of dementia. <http://www.alz.co.uk/research/world-report-2012>
19. Alzheimer's Disease International. World Alzheimer Report 2013: An analysis of long-term care for dementia. <http://www.alz.co.uk/research/world-report-2013>

## CHAPTER 3

## Prevalence and costs of dementia



The 18 member associations of ADI in the Asia Pacific region are located in Australia, Bangladesh, China, Chinese Taipei, Hong Kong SAR, India, Indonesia, Japan, Macau SAR, Malaysia, Nepal, New Zealand, Pakistan, Philippines, Singapore, Republic of Korea, Sri Lanka and Thailand. The APRO is based in Singapore. There are 21 other countries or territories in the region that either do not have Alzheimer associations or are not members of ADI.

The population of the Asia Pacific region is estimated as 4 billion people based on ADI's categorisation of the region. Accordingly, estimates show that the population over 60 years in the region is estimated at more than 11%<sup>1,2</sup>. It is expected that in 2050 a quarter of the total population in the Asia Pacific region will be aged 60 years or older. The increase in ageing also extends to the oldest-old or those aged 80 and over. The proportion of the oldest-old in the Asia Pacific region has increased dramatically; in 1990, the proportion of those aged 80 years and over was 0.8% which rose to 1.4% in 2012 with projections indicating this will increase to 4.4% by 2050<sup>1,2</sup>.

### Prevalence in the Asia Pacific region

Prevalence refers to the percentage of people with dementia in a population at a given point in time or over a certain time period. International epidemiological studies

make it clear that dementia occurs in every country of the world.

The results of prevalence studies conducted globally vary due to the differing methods employed by researchers. However, all studies have shown a rise in the prevalence rates with age. Although dementia can occur at any age, it is rare for people under the age of 60 years to be affected. As the global population continues to age, there will be relatively more people in the age groups most at risk of dementia. In the absence of effective prevention and treatment, the increase in the number of people with dementia will come about as a simple consequence of an increase in the size of the population most at risk i.e. those aged 60 years and over.

In 2013, ADI adjusted its prevalence estimates due to the availability of further data from several countries. Globally, the estimated number of people with dementia in 2013 was 44 million. By 2030 there will be 76 million people with dementia and 135 million by 2050.

In the Asia Pacific Region, the number of people with dementia will increase from 23 million in 2015 to almost 71 million by 2050. That means by 2050 more than half of the people with dementia worldwide (135 million) will live in this region.

Table 3.1 summarises the prevalence and number of people with dementia in individual countries of the Asia Pacific region.

Table 3.1  
**Estimated number of people with dementia**

	Projected Population ('000) <sup>+</sup>	Estimated Number of people with Dementia ('000)		
		Y2015	Y2030	Y2050
<b>ADI Members</b>				
Australia	23,923	328	520	864
Bangladesh	160,411	460	834	2,193
China, P.R.	1,401,587	10,590	18,116	32,184
China, Hong Kong SAR	7,314	115	212	436
China, Macau SAR	584	4	11	26
Chinese Taipei	23,380	260	461	840
India	1,282,390	4,031	6,743	12,542
Indonesia	255,709	1,033	1,894	3,979
Japan	126,818	3,014	4,421	5,214
Malaysia	30,651	123	261	590
Nepal	28,441	78	134	285
New Zealand	4,596	60	96	154
Pakistan	188,144	450	712	1,422
Philippines	101,803	301	568	1,149
Singapore	5,619	45	103	241
Republic of Korea	49,750	462	974	2,113
Sri Lanka	21,612	147	262	463
Thailand	67,401	600	1,117	2,077
<b>ADI members total</b>	<b>3,780,133</b>	<b>22,100</b>	<b>37,438</b>	<b>66,772</b>
<b>Non ADI members*</b>	211,660	1,179	1,970	4,209
<b>Total Asia Pacific</b>	<b>3,991,793</b>	<b>23,279</b>	<b>39,409</b>	<b>70,981</b>

+ Population projection from ADI based on UN data (<http://esa.un.org/wpp/>)

\* Non ADI members consists of 21 countries/territories

Prevalence and cost data from ADI's World Alzheimer Report 2009, World Alzheimer Report 2010 and G8 policy brief 2013. As the prevalence rates and the number of people with dementia are derived from projected population figures, some data may vary from different reports and analyses.

## Economic cost

The worldwide costs associated with dementia are tremendous with estimates indicating that in 2010 US\$604 billion was spent on the disease. These costs related to informal care (such as unpaid family carers), social care (community and residential care) and medical care (treatments in primary and secondary care)<sup>3</sup>.

For the Asia Pacific region, it is estimated that the total costs associated with dementia are US\$185 billion. These figures are likely to increase as the numbers of people with dementia grow, and the mounting societal

demand in countries with emerging economies and large populations in the region including India, China and Indonesia.

Based on the 2015 data, 64% of the total region's costs of dementia care were estimated to be in the advanced economies, which contain 17% of the prevalence.

The costs associated with caring for a person with dementia differ radically between countries and are dependent upon such factors as urbanisation, cultural and family structures, public health infrastructure, care services, gross domestic product, and government.

Table 3.2  
**Estimated costs of dementia**

	Estimated aggregated costs of dementia in 2015 (millions US\$)			
	Medical Cost	Non-Medical Cost	Informal Care Cost	Total
<b>ADI Members</b>				
Australia	\$ 794	\$ 6,413	\$ 5,685	\$ 12,892
Bangladesh	\$ 86	\$ 42	\$ 193	\$ 321
China, P.R.	\$ 9,055	\$ 4,483	\$ 31,081	\$ 44,619
China, Hong Kong SAR	\$ 190	\$ 1,536	\$ 1,501	\$ 3,227
China, Macau SAR	\$ 11	\$ 91	\$ 56	\$ 158
Chinese Taipei	\$ 412	\$ 3,326	\$ 3,252	\$ 6,990
India	\$ 1,353	\$ 670	\$ 2,597	\$ 4,620
Indonesia	\$ 773	\$ 383	\$ 621	\$ 1,777
Japan	\$ 6,025	\$ 48,684	\$ 38,531	\$ 93,240
Malaysia	\$ 260	\$ 128	\$ 317	\$ 705
Nepal	\$ 15	\$ 8	\$ 29	\$ 52
New Zealand	\$ 187	\$ 678	\$ 334	\$ 1,199
Pakistan	\$ 160	\$ 79	\$ 403	\$ 642
Philippines	\$ 167	\$ 83	\$ 349	\$ 599
Singapore	\$ 89	\$ 721	\$ 854	\$ 1,664
Republic of Korea	\$ 455	\$ 3,679	\$ 4,542	\$ 8,676
Sri Lanka	\$ 99	\$ 49	\$ 82	\$ 230
Thailand	\$ 672	\$ 332	\$ 806	\$ 1,810
<b>ADI members total</b>	<b>\$ 20,803</b>	<b>\$ 71,385</b>	<b>\$ 91,234</b>	<b>\$ 183,422</b>
<b>Non ADI members</b>	<b>\$ 372</b>	<b>\$ 203</b>	<b>\$ 871</b>	<b>\$ 1,446</b>
<b>Total Asia Pacific</b>	<b>\$ 21,175</b>	<b>\$ 71,589</b>	<b>\$ 92,104</b>	<b>\$ 184,868</b>

Those countries with a low or middle income invariably have larger costs associated with informal care for the person with dementia whilst care costs in high income countries are relatively evenly distributed across informal and social care<sup>4</sup>.

Table 3.2 provides an estimate of the aggregated cost of dementia for 2015. These figures are adjusted with two approaches: estimated change in Consumer Price Index (CPI) - (main option) and of Gross Domestic Product (GDP) - (sensitivity analysis). The major source of figures is the IMF/World Economic Outlook between 2010 and 2013 with assumed linear trends between 2013 and 2015. No new cost of illness studies are used for the update and no new major assumptions regarding care organisation and amounts of informal care are used.

## References

1. United Nations ESCAP. Population Trends in Asia and the Pacific. Nov 2013 <http://www.unescapsdd.org/files/documents/SPPS-Factsheet-Population-Trends-v3.pdf>
2. World Health Organisation. Global Health Observatory website retrieved 21 April 2014. <http://apps.who.int/gho/data/node.country>
3. Alzheimer's Disease International. World Alzheimer Report 2010: The Global Economic Impact of Dementia. <http://www.alz.co.uk/research/world-report-2010>
4. World Health Organization. (2012). Dementia: a public health priority. [http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1)

## CHAPTER 4

# Strategies to Address the Dementia Epidemic



Figure 4.1  
Dementia pathway

## Dementia pathways

### Background

Dementia pathways provide a way of conceptualising the journey of dementia as well as setting out the needs for services and supports at different stages in the development of dementia. Developing an integrated care pathway also provides an opportunity to develop a policy framework which provides support and action at all stages of the disease.

At the same time, it must be recognised that no pathway will be able to encapsulate all of the diverse needs of people with various types of dementia and other needs and circumstances. For example the pathway may be somewhat different for people from different communities, age groups, and personal circumstances. The pathway described in Figure 4.1 has been developed from a number of sources<sup>1,2,3</sup>. This pathway provides a framework that could be adapted to local service delivery contexts and community needs. (An example of the adoption of the pathway approach at a local level in Australia can be found here: <http://www.grampiansml.com.au/dpp/>)



## Awareness

Poor community understanding of dementia and confusion about the differences between dementia and normal ageing can contribute to delays in getting access to appropriate treatment and services. There is a need to address community awareness about dementia and to provide access to timely and appropriate information for individuals who are concerned about their memory. People with dementia and health care professionals need to be made aware of the legal rights of a person with dementia.

There is also a need to tackle the stigma and social isolation which can occur for people with dementia through initiatives which promote social engagement such as the development of 'dementia-friendly communities'. This includes awareness activities for front-line staff in community service organisations, police, banks, transport and emergency services to support people with dementia to remain active in their local communities.

Action is also needed to address population risk factors such as hypertension, smoking, obesity, and excessive use of alcohol. Public health campaigns are needed to promote messages around dementia-risk reduction and the links between other chronic diseases and dementia.

## Diagnosis

People with dementia often experience significant delays in getting access to a formal diagnosis. Studies conducted over the last 10 years in high income countries show that only approximately a third of cases of dementia are routinely recognised and documented in primary care case note records. There is little data available from middle to low income countries, but there is some evidence to suggest rates of diagnosis may be even lower in those countries<sup>4</sup>.

Earlier diagnosis enables people with dementia to plan ahead while they still have the capacity to make important decisions about their future care. In addition, they and their families can receive timely practical information, advice and support. Only through receiving a diagnosis can they get access to available drug and non-drug therapies that may improve their cognition and enhance their quality of life. They can also, if they choose, participate in research for the benefit of future generations.

There is a need to develop clear diagnostic pathways which are appropriate in the local service context to ensure that people with dementia have timely access to trained health care professionals who can provide diagnosis, referral and information. For people with dementia and carers there is a need for access to clear information about dementia, the range of support services available, and information to support planning ahead (care, financial and lifestyle). There needs to be sound legal information about appropriate steps in regard

to issues around driving, guardianship, and power of attorney.

## Management and care

There is a need to ensure timely access to care, support and information services to meet changing and fluctuating needs of the person with dementia and to support the person to maintain their independence as long as possible. People with dementia and their families need access to a range of care services including in-home community care support, residential care, and respite services. It is important that services are tailored to the needs of the person with dementia and provide options for continued social engagement and access to meaningful activities. A key worker or case management model can provide people with dementia and their families with access to support from the moment of diagnosis and provide assistance in navigating the service pathways.

Service providers need support and training to provide person-centred dementia care including training and support on the management of behavioural and psychological symptoms of dementia including psychosocial approaches. The person with dementia should be included as much as possible in decisions about their care and support. In addition, there should be a focus on supporting the person with dementia to maximise their existing cognitive strengths and maintaining functional abilities, using restorative approaches.

Appropriate care also needs to be ensured within the hospital system as often hospitals are confusing and confronting places for people with dementia. People with dementia are often hospitalised due to a fall or other illness or infection. It is imperative that the hospital recognise that the person has dementia and ensure that appropriate strategies are in place to provide adequate support and care. Strategies to improve care include audits of the physical design of the hospital, dementia training for staff, and methods of identification and screening for people at risk of dementia.

## End of life care

Advance care planning including legal and care planning should be done soon after diagnosis so that the person with dementia can have an opportunity to document their wishes. Appropriate and timely support and advice needs to be provided to support this planning. Aged care providers and other health professionals should request information about end of life care plans when they begin providing services to a person with dementia.

People with dementia should have access to appropriate end of life care which is in line with their previously expressed wishes or documented advance care plans. Carers should be empowered with information about the legal options at end of life (for example, withdrawal of treatment, issues around nutrition and hydration).

Table 4.1  
Strategies for the care of people with dementia

Strategies	Scenario A Low level of resources	Scenario B Medium level of resources	Scenario C High level of resources
<p>1. Establish national policies, programs and legislation (including legislation to protect the legal rights of people with dementia)</p>	<p>Review legislation based on understanding of dementia and human rights considerations. Formulate dementia care programs and policies including</p> <ul style="list-style-type: none"> <li>• Legal framework to support and protect those with impaired mental capacity</li> <li>• Inclusion of people with dementia in disability benefit schemes</li> <li>• Inclusion of carers in compensatory benefit schemes</li> </ul> <p>Establish health and social care budgets for older people.</p>	<p>Implement dementia care policies at national and sub national levels. Establish health and social care budgets for dementia care. Ensure legislation is working well to protect the legal rights of people with dementia including power of attorney and guardianship.</p>	<p>Ensure fairness in access to primary and secondary health care services, and to social welfare programs and benefits. Ensure policies are targeting social issues as well as health and care needs. Ensure people from vulnerable groups (homeless, living alone etc.) are appropriately supported.</p>
<p>2. Increase community awareness and information</p>	<p>Support non governmental organisations to provide information and awareness activities about dementia. Use social media and other cost effective techniques to promote awareness and positive attitudes towards dementia.</p>	<p>Use the media (including social media) to promote awareness of dementia, foster positive attitudes, reduce stigma and ensure people with dementia and their families know where to access assistance.</p>	<p>Launch public campaigns for early help-seeking, recognition and appropriate management of dementia. Develop initiatives around dementia-friendly communities and organisations to tackle stigma and social isolation.</p>
<p>3. Promote dementia risk reduction strategies including within primary care and link with other health promotion activities</p>	<p>Incorporate dementia risk reduction messages with any currently funded health promotion activities</p>	<p>Raise awareness about dementia risk reduction through developing information and resources.</p>	<p>Fund a national dementia risk reduction awareness program including an awareness campaign, website and help sheets. Ensure that dementia risk reduction is incorporated into other health promotion activities. Monitor effectiveness of prevention programs.</p>
<p>4. Ensure access to assessment and treatment in primary care</p>	<p>Recognise dementia care as a component of primary health care. Include the prevention, 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).</p>	<p>Develop locally relevant training materials, electronic resources and locally adapted guidelines. Provide refresher training to primary care physicians (100% coverage in 5 years). Increase availability of medications for the treatment of dementia in all health care settings.</p>	<p>Improve effectiveness of diagnosis and management of dementia in primary health care. Involve nurses in assessment and support of people with dementia. Reduce time to diagnosis and ensure appropriate referral including timely access to specialists as required. Ensure that there are adequate business incentives for assessment and treatment within primary care.</p>
<p>5. Establish services to support family carers</p>	<p>Support the formation of self-help groups. Develop basic educational and training interventions for carers. Fund schemes for nongovernmental organisations.</p>	<p>Provide full access to training, education and support programs for family carers and evaluate their effectiveness.</p>	<p>Provide carers with access to a range of tailored interventions, support and information. Key workers to help person with dementia and carers navigate the whole journey.</p>



Table 4.2

**Examples of national dementia plans**

National plan	Early detection	Access to diagnosis	Stigma reduction
Australia	<ul style="list-style-type: none"> <li>Develop and validate effective cognitive screening/assessment tools</li> <li>Development and training in the primary care setting</li> </ul>	<ul style="list-style-type: none"> <li>Service plan development: mapping service pathways, assessing service gaps and future analysis</li> <li>Assistance in community care setting</li> <li>Address specific barriers and target vulnerable populations for diverse service models</li> </ul>	<ul style="list-style-type: none"> <li>Administer dementia literacy survey</li> <li>Community awareness programmes with key messages</li> </ul>
Republic of Korea	<ul style="list-style-type: none"> <li>National coverage for public health centres</li> </ul>	<ul style="list-style-type: none"> <li>National Dementia Centre</li> <li>Increase number of trained dementia specialists</li> </ul>	<ul style="list-style-type: none"> <li>Public awareness</li> <li>Media cooperation</li> </ul>

Palliative care services should be available both in the community and residential care settings and aged care staff should have training on provision of appropriate end of life care for people with dementia.

### Family and carer support

Throughout the dementia journey, including after the death of the person with dementia, there needs to be adequate support for families and informal carers. In most countries it is the family carer who provides the majority of the care and support to people with dementia in the community. Caring responsibilities can have significant impacts on the physical and mental health of the carer as well as significant financial implications due to the impact on employment.

Carers need access to information and counselling to assist in adjusting to the diagnosis and caring role as well as the subsequent changes in the person with dementia. The carer also needs practical advice and support in terms of day to day caring responsibilities including psychosocial approaches to responding to behavioural and psychological symptoms of dementia. Access to support groups or information sessions through local Alzheimer associations can be invaluable in providing both support and opportunities for social interaction. Finally there should be some respite care available that allows family carers to take a break from their responsibilities.

In countries with limited resources it is not possible to create this whole pathway at once. Therefore, ADI developed the Kyoto Declaration in 2004 as a tool for priority setting based on the level of resources. An amended version can be found in Table 4.1.

### Strategies to address dementia by country

The economic and social impact of dementia has led countries at the forefront of global ageing such as Australia, countries in Western Europe, Republic of Korea and Japan to initiate national programmes and strategies to contend with the increasing numbers of people with dementia. Table 4.2 details aspects of national dementia

plans by Australia and Republic of Korea in improving areas such as early detection, access to diagnosis and stigma reduction.

The growing financial impact of dementia was one of the primary reasons for holding a G8 summit on dementia in London in December 2013. The G8 Ministers of Health called for increased research investment, better collaboration between industry and academia, improvements in health systems and a societal response towards awareness and understanding of dementia. A number of follow up meetings are planned in 2014 and 2015 with the inclusion of lower and middle-income countries.

Alzheimer's Disease International recommends that all countries in the Asia Pacific region be included in this process and that every country should develop its own plan or strategy on how to deal with dementia now and in the future. A list of the current national plans on dementia are available on the Alzheimer's Disease International website (<http://www.alz.co.uk/national-plans>) which is regularly updated. A report comparing seven of the plans was produced in 2012, a sample of which is shown in Table 4.2<sup>5</sup>.

### ADI member profiles and environment

The 18 countries/territories in the Asia Pacific region where ADI has member associations have varying levels of health care, social service, community support and government prioritisation. These member associations have each contributed a country and organisation profile which provides insights including the status of national dementia plans, research, services, training and resources available for people with dementia and their families.

Individual country/territory profiles are found in the Annex of this report. Each profile also includes information such as the background of the association, status of national dementia action plans, types of services provided and government spending on community programmes and research.

Table 4.3  
List of Member Associations as of June 2014

Country/Territory	Name of Association	Website
Australia	Alzheimer's Association Australia	<a href="http://www.fightdementia.org.au">www.fightdementia.org.au</a>
Bangladesh	Alzheimer Society of Bangladesh	<a href="http://www.alzheimerbd.com">www.alzheimerbd.com</a>
China, P.R.	Alzheimer's Disease Chinese	<a href="http://www.adc.org.cn">www.adc.org.cn</a>
China, Hong Kong SAR	Hong Kong Alzheimer's Disease Association	<a href="http://www.hkada.org.hk">www.hkada.org.hk</a>
China, Macau SAR	Macau Alzheimer's Disease Association	<a href="http://www.mada.org.mo">www.mada.org.mo</a>
Chinese Taipei	TADA	<a href="http://www.tada2002.org.tw">www.tada2002.org.tw</a>
India	Alzheimer's and Related Disorders Society of India	<a href="http://www.ardsi.org">www.ardsi.org</a>
Indonesia	Alzheimer Indonesia	<a href="http://www.alzheimerindonesia.org">www.alzheimerindonesia.org</a>
Japan	Alzheimer's Association Japan	<a href="http://www.alzheimer.or.jp">www.alzheimer.or.jp</a>
Korea, Republic of	Alzheimer's Association Korea	<a href="http://www.alzza.or.kr">www.alzza.or.kr</a>
Malaysia	Alzheimer's Disease Foundation Malaysia	<a href="http://www.adfm.org.my">www.adfm.org.my</a>
Nepal	Alzheimer's and Related Disorders Society of Nepal	<a href="http://www.ardsnepal.org">www.ardsnepal.org</a>
New Zealand	Alzheimers New Zealand	<a href="http://www.alzheimers.org.nz">www.alzheimers.org.nz</a>
Pakistan	Alzheimer's Pakistan	<a href="http://www.alz.org.pk">www.alz.org.pk</a>
Philippines	Alzheimer's Disease Association of the Philippines	<a href="http://www.alzphilippines.com">www.alzphilippines.com</a>
Sri Lanka	Lanka Alzheimer's Foundation	<a href="http://www.alzlanka.org">www.alzlanka.org</a>
Singapore	Alzheimer's Disease Association	<a href="http://www.alz.org.sg">www.alz.org.sg</a>
Thailand	Alzheimer's and Related Disorders Association of Thailand	<a href="http://www.azthai.org">www.azthai.org</a>

## References

1. KPMG (2011). Dementia Services Pathways- an essential guide to effective service planning
2. NICE (2011). Dementia Pathway. (<http://pathways.nice.org.uk/pathways/dementia>)
3. NSW Health (2011). NSW Dementia Services Framework 2010-2015.
4. Alzheimer's Disease International. World Alzheimer Report 2011: The benefits of early diagnosis and intervention. <http://www.alz.co.uk/research/world-report-2011>
5. Alzheimer's Disease International. National Alzheimer and Dementia Plans, Planned Policies and Activities <http://www.alz.co.uk/sites/default/files/national-alzheimer-and-dementia-plans.pdf>

## CHAPTER 5

# Risk reduction in dementia



There is no evidence strong enough at this time to claim dementia can be prevented completely, but there is persuasive evidence that risk reduction is achievable at a population level and has the potential to reduce the future impact of the illness. This will require a whole society approach, and substantial investment in dementia prevention research and initiatives.

### The evidence

Older age is the most important risk factor for dementia, with prevalence increasing exponentially after the age of 65<sup>1</sup>. Genetics is another non-modifiable risk factor, but only a small proportion of dementia cases are thought to be directly inherited and caused by gene mutations; the majority of cases are sporadic and likely to result from a combination of genetic and environmental influences<sup>2</sup>.

There is now a large body of research evidence demonstrating that several health and lifestyle factors are associated with dementia incidence<sup>2</sup>. Factors increasing the risk of developing dementia include smoking, obesity, diabetes, hypertension and high total cholesterol<sup>2,3</sup>. Higher education and cognitively stimulating activity, regular physical activity, social activity, moderate alcohol consumption and a healthy diet are associated with lower dementia risk<sup>2,3</sup>.

These modifiable lifestyle and medical risk factors for dementia are often conceptualised as delaying factors that can postpone the onset of dementia<sup>3</sup>. A lifestyle that promotes heart and brain health can build brain reserve, so that cognitive function remains intact for longer in the face of neurodegenerative disease<sup>3</sup>. Recent research

findings also suggest better heart and brain health may delay development and progression of Alzheimer's disease and cerebrovascular disease<sup>2</sup>.

It is unlikely that interventions addressing risk and protective factors will lead to an absolute prevention of dementia. However, postponement of the clinical onset of dementia to a later age and better prevention at the population level should be achievable and could significantly reduce dementia prevalence<sup>4,5</sup>. Community surveys suggest low levels of knowledge about the potential for dementia risk reduction<sup>6</sup>. Therefore, investments are required at a population level, to encourage and teach engagement in lifestyle changes that may delay the onset of dementia<sup>2,4</sup>.

### The potential for prevention

The impact of a breakthrough treatment that delayed the onset of dementia has been estimated in several models of future prevalence<sup>7</sup>. A treatment that delayed onset by 5 years would reduce dementia prevalence in 2050 by 40-50%, depending on how soon it became available. Even delaying onset by 2 years would mean around 20% fewer people living with dementia in 2050. The hypothetical treatment to delay onset might be a vaccine, a medication or a combination of medications, or a change in diet, exercise or other lifestyle behaviours<sup>8</sup>.

Previous trials of dementia-modifying drugs have not shown benefit, and even if current trials prove successful, these drugs will not eradicate all causes of dementia and are unlikely to come onto the market before 2020<sup>4</sup>. While dementia remains incurable, health and lifestyle

approaches offer some hope of reducing the expected future impact on individuals, society, healthcare systems and economic costs.

It was recently estimated that up to half of Alzheimer's disease cases are potentially attributable to seven modifiable risk factors (diabetes, midlife hypertension, midlife obesity, depression, physical inactivity, smoking and cognitive inactivity)<sup>9</sup>. This study further estimated that 3 million cases of Alzheimer's disease could be prevented worldwide by reducing by 25% the incidence of these risk factors. A French study concluded that increasing intellectual activity and fruit and vegetable consumption and eliminating depression and diabetes are likely to have the biggest impact on reducing the incidence of dementia, outweighing even the effect of removing the principal known genetic risk factor for Alzheimer's disease<sup>10</sup>.

Dementia cannot be definitively prevented, but the evidence to date clearly suggests that a multifactorial strategy targeting cognitively and physically active lifestyle promotion and effective cardiovascular risk factor treatment is likely to lower the incidence of dementia compared with the status quo. There are no guarantees that an individual will not develop dementia, but we can provide recommendations on how to best lower an individual's chances of developing the disease. Although this may appear a modest gain, the population and societal impacts could be enormous<sup>2,4,5</sup>.

## Links with other diseases and their effective management

Cardiovascular disease, diabetes, obesity, hypertension and high cholesterol are each associated with an increased risk of developing dementia. The occurrence of vascular risk factors during midlife increases the risk of late-life dementia, suggesting these factors exert their effects on the brain over a long period of time. Whether effective treatment of vascular risk factors prevents dementia has not been sufficiently studied. Because their treatment is important for many other health outcomes, long term trials of treatment for dementia prevention may not be ethical. However, because effective vascular risk factor treatment can reduce the risk of cardiovascular disease or stroke, it is very likely to also reduce dementia risk<sup>11</sup>.

Around 2% of Alzheimer's disease cases worldwide<sup>9</sup>, and almost 5% of mild cognitive impairment and dementia cases in a French cohort<sup>10</sup>, were estimated to be attributable to diabetes. If the incidence of diabetes continues to increase, so will its impact on dementia prevalence. Despite a lower relative contribution to dementia than some other risk factors, diabetes is common and is treatable, so interventions to prevent and effectively treat diabetes are likely to have a high impact and be cost effective for dementia prevention<sup>10</sup>, in addition to benefits for other chronic diseases.

More substantial evidence is available for treatment of hypertension in midlife, which is associated with increased dementia risk and was estimated to account for 5% of Alzheimer's disease cases<sup>10</sup>. There is reasonable evidence that enhanced blood pressure management in both midlife and late life can reduce dementia incidence, with longer duration of treatment conferring greater protection<sup>5,11</sup>.

A history of depression is also considered a risk factor for dementia. As with vascular risk factors, studies of whether effective management of depression can reduce dementia risk are lacking and may not be practical. It has been estimated that 10% of Alzheimer's disease cases worldwide are potentially attributable to depression<sup>9</sup>. In a French study, elimination of depression from the elderly population was estimated to lead to a 10% reduction in the number of new cases of mild cognitive impairment and dementia, leading the authors to recommend screening for and early treatment of depression as a dementia prevention strategy<sup>10</sup>.

A substantial proportion of dementia cases are potentially attributable to treatable conditions including depression, hypertension, obesity and diabetes, highlighting the importance of identification and management of these conditions. Importantly, this needs to begin in midlife to have an impact on late life dementia incidence. Research into strategies for reducing multiple risk factors to prevent dementia is needed, as are public health campaigns targeted at dementia risk factor modification at individual and population levels.

## References

1. Australian Institute of Health and Welfare (2012). Dementia in Australia. Cat. No. AGE 70. AIHW: Canberra.
2. Farrow M, O'Connor E (2012). Targeting brain, body and heart for cognitive health and dementia prevention. Alzheimer's Australia Paper 29. Alzheimer's Australia: Canberra.
3. Hughes TF, Ganguli M (2009). Modifiable midlife risk factors for late-life cognitive impairment and dementia. *Curr Psychiatry Rev*, 5:73-92.
4. Brodaty H, Breteler MMB, DeKosky ST, et al (2011). The world of dementia beyond 2020. *J Am Geriatr Soc*, 59(5):923-927.
5. Valenzuela M (2012). Brain and heart targets for better dementia prevention. *Medicine Today*, 13(2): 38-43.
6. Farrow M (2008). Dementia risk reduction: What do Australians know? Alzheimer's Australia: Canberra.
7. Vickland V, Morris T, Draper B, et al (2012). Modelling the impact of interventions to delay the onset of dementia in Australia. A report for Alzheimer's Australia. Canberra: Alzheimer's Australia
8. Alzheimer's Association (2010). Changing the trajectory of Alzheimer's disease: a national imperative. Washington DC: Alzheimer's Association.
9. Barnes DE, Yaffe K (2011). The projected effect of risk factor reduction on Alzheimer's disease prevalence. *Lancet Neurol*, 10(9):819-828.
10. Ritchie K, Carriere I, Ritchie CW, et al (2010). Designing prevention programmes to reduce incidence of dementia: prospective cohort study of modifiable risk factors. *BMJ*, 341:c3885.
11. Gorelick PB, Scuteri A, Black SE, et al (2011). Vascular contributions to cognitive impairment and dementia. A statement for health-care professionals from the American Heart Association/American Stroke Association. *Stroke*, 42(9):2672-2713.

## CHAPTER 6

# Conclusions and recommendations



The ageing of the global population will see the number of people living with dementia rapidly increase in the coming years. As the population of the Asia Pacific region accounts for nearly 60% of the world's total population, there will be a need to develop health and care systems that can meet the growing number of people living with dementia.

A number of countries around the world have taken the first step in tackling dementia by formulating strategies and plans on key areas of action. The updated Kyoto Declaration can be utilised by those countries looking to create their own strategy for dementia – this will be integral to ensure that countries are adequately prepared to support those living with dementia.

ADI recommends action in the following areas by governments, non-governments and other stakeholders in the Asia Pacific region:

1. Provide education and awareness about Alzheimer's disease and other types of dementia highlighting that dementia is not a normal part of ageing but a disease of the brain.
2. Improve the quality of life of people living with dementia by providing education to family members, paid carers and other health care professionals to ensure that the best quality of care is delivered to people living with dementia.
3. Promote the development of health and community care systems to deal with an increasing number of people with the disease. To the best extent possible, ensure that health and community care systems are adequately equipped to provide care and treatment, provide education or professional development to family, paid carers and health care workers, and adequately and continuously invest in health and community care systems.
4. Raise awareness of prevention and risk reduction strategies which may delay the onset of the disease for some individuals and reduce future numbers of people with dementia.
5. Countries to develop national dementia action plans detailing key areas for action including research, awareness and education, improving quality of care, prevention and risk reduction and assessment and diagnosis. The Kyoto Declaration provides a framework of possible strategies for countries to consider.
6. Promote and support further research into the health and care systems in lower and middle income countries in the development of health policy.

## Annex A: AUSTRALIA

Estimated Number of People with Dementia ('000)			Estimated Costs of Dementia in Y2015 US\$ (mil)			
Y2015	Y2030	Y2050	Medical	Non-Medical	Informal Care	Total
328	520	864	\$ 794	\$ 6,413	\$ 5,685	\$ 12,892

(data from ADI 10/66 Dementia Research Group)

### Country Profile contributed by

Alzheimer's Australia (www.fightdementia.org.au)

### Background

Alzheimer's Australia is a federated organisation based in Australia with an office in each state and territory - Victoria (VIC), New South Wales (NSW), Australian Capital Territory (ACT), Queensland (QLD), Tasmania (Tas), South Australia (SA), Northern Territory (NT), Western Australia (WA).

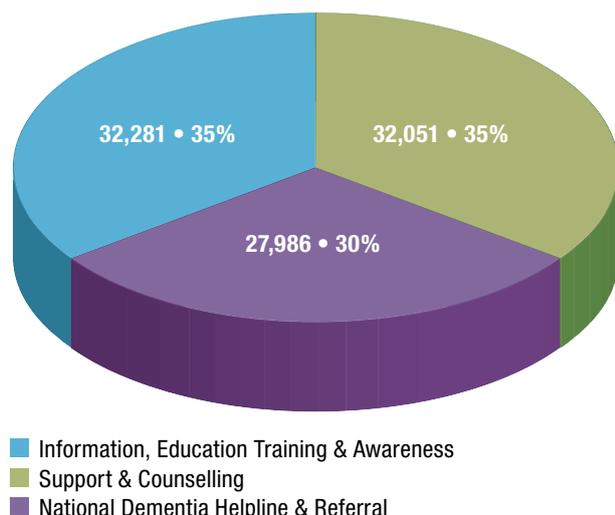
Altogether, there are 23 local/regional offices that employ more than 600 paid employees.

### Number of people supported

During the financial year 2012-13, 92,318 people were supported by the Federal Government through the National Dementia Support Programs (NDSP) administered by Alzheimer's Australia. Figure 2 represents the number of people who accessed particular types of support through NDSP:

Figure A.1

**National Dementia Support Programs in Australia:**  
NDSP Services Delivered to Participants July 2012 - June 2013



In the same year information was accessed through the Fight Dementia website (www.fightdementia.org.au) by 803,075 people, which includes people with dementia, their carers, family members and service providers.

### National dementia strategy/plan

At the national level there have been three major initiatives which have established dementia as a national health priority area.

First, in 2005 the then Government implemented the Dementia Initiative – making dementia a health priority with a commitment to additional funding of A\$320 million over five years. This funding was for a range of activities including dementia training, the establishment of three Dementia Collaborative Research Centres, the introduction of dementia home care packages for those with high level needs and additional funding for the programmes of Alzheimer's Australia. This funding has continued since 2010 up to the present time.

Second, as part of the 2012 Aged Care Reforms, the Government made a commitment of A\$273 million over five years to tackle dementia. This funding is to be used to achieve timely diagnosis, better dementia care in acute hospitals, younger onset dementia key workers and supplements in both community and residential care to recognise the additional costs of dementia. In addition, the Government invested in the national roll out of a dementia risk reduction programme – Your Brain Matters.

Thirdly, as part of the Aged Care Reform package, a *National Framework for Action on Dementia* is being finalised. Alzheimer's Australia has been advocating for the framework to be finalised by the new Government as soon as possible.

### Healthcare and social care professionals

There are a range of health care professionals involved in the care of older people, including people with dementia, in Australia. Direct care professionals providing community services to older people in 2012 included approximately 76,000 care workers, 7,600 registered nurses, 3,600 enrolled nurses, 4,000 allied health professionals, 2,000 allied health assistants and 200 nurse practitioners. Therefore approximately 93,400 direct care staff were required to provide community aged care services within the Australian community in 2012. Most of these direct care staff would have provided care to people with dementia.

In 2012 it was estimated that there were 147,000 direct care staff in residential aged care facilities, which included 100,000 personal care attendants, 22,000

Table A.1  
Government spending on community services

Type of Dementia Care	Estimate of Australian Government Expenditure (AUD)
Community Care	\$210.2 million
Residential Care (solely care for dementia and not including co-existing conditions)	\$1.1 billion
Acute Care (where dementia is the main diagnosis)	\$144.5 million
Total health and aged care system expenditure for dementia care	\$4.9 billion

The above cost estimates are for the 2009-10 financial year and are taken from the Australian Institute of Health and Welfare (2012) *Dementia in Australia* publication.

registered nurses, 17,000 enrolled nurses, 2,700 allied health professionals, 2,000 allied health assistants and 300 nurse practitioners.

Care professionals with a range of expertise and experience work for Alzheimer's Australia to provide dementia specific education, information, support and counselling, to people with dementia, their carers and family.

### Awareness raising

Alzheimer's Australia conducts a range of awareness and public education activities, which include national speaking tours, publications, media involvement, memory walks and social media participation. The centrepiece of these activities is the ongoing Fight Dementia campaign which has established a programme of action on dementia 2014-2016 together with national branding which is consistent across all members of Alzheimer's Australia.

### Resources

Forms of dementia resources available through Alzheimer's Australia include online resources, publications which include publications such as the Quality Dementia Care series and conference communiqués, research papers, journal articles, help sheets, newsletters, books, videos, brochures, posters and submissions to the Australian Government.

A substantial amount of information is on the website ([www.fightdementia.org.au](http://www.fightdementia.org.au)).

### Training

Formal and informal training is provided through Alzheimer's Australia. Formal training for service providers includes seminars by local and international experts, workshops on a variety of topics and certified courses in dementia care. Informal training provided by Alzheimer's Australia for people with dementia, their carers, family and friends, includes early intervention programs, carer education courses, workshops and seminars.

The Dementia Care Essentials project, a government initiative, provides funding for the delivery of dementia specific training to aged care workers across all states and territories. From 2011 to 2013, approximately 12,000 aged care workers received this training. Also in 2012 to 2013, A\$3.9 million of government funding was provided to five Dementia Training Study Centres to develop and up-skill the dementia care workforce and transfer knowledge into practice.

### Services

A range of community services are administered by Alzheimer's Australia, which include the National Dementia Helpline, Younger Onset Dementia Key Worker Program, consumer support groups, counselling, Special Access Liaison Offices, information sessions, resource development and distribution, library services for dementia resources (including online) and Dementia Behaviour Management Advisory Services.

### Government funding within Alzheimer's Australia

The National Office receives Federal Government funding to administer a number of national programs to provide services to people with dementia, families and carers as well as awareness activities for the services sector, health professionals and the general public. The services are provided by our state and territory members as sub-contractors to the funding agreements. The funding for these programs covers 100% of the costs.

Independently, individual States and Territories also receive funding from Federal and State Government to provide a range of services including social support, counselling, respite, education and awareness activities.

## Other community and residential services

### Community services

It is estimated that 70% of all people with dementia in Australia live in the community and therefore it is important that a range of community services provided by the government, not-for-profit or privately run organisations are available for these people to help them remain living in the community. Approximately 50,000 people with dementia in 2010 received Home and Community Care services, which are funded by the government.

Community and home care services for older people, including those with dementia, can be obtained through the Federal Government funded Aged Care System, as Home Care Packages. More than 17,000 people with dementia accessed a Home Care Package in 2010. A range of supports are included in these home care packages such as assistance with personal care, domestic duties, shopping, clinical care, transport, outings, home respite, social activities and accompanying people to appointments.

There are four different levels of Home Care Packages that are allocated depending on the support needs of the individual. Approximately 4,000 people with dementia accessed the highest level of Home Care Package support (Level 4, formerly known as the Extended Aged Care at Home Package) in 2011-12.

People with dementia are eligible for the Dementia and Cognition Supplement in Home Care Packages, which provides additional financial assistance to service providers. This supplement was developed in recognition of the additional costs associated with caring for people with dementia and mental health conditions.

### Residential services (e.g. nursing homes) and long term care

Approximately 112,000 people in residential aged care facilities in Australia have dementia, which equates to about 53% of all residents. Residential services are subsidised by the Federal Government and provided by not-for-profit (60%), private for-profit (29%) or state and local government (11%) facilities. The Federal Government spends an estimated A\$1.1 billion on dementia care in residential facilities. The amount subsidised by the government for these services depends on the level of care that the person requires (low or high), their income and assets, and their pensioner status.

Alzheimer's Australia works with the Government and other associations to improve care for people with dementia by providing training, information and recommendations based on research and consumer experiences. Alzheimer's Australia also collaborates on government policy and advocacy work with other organisations, who have similar views and goals.

### Research funding

The Australian Government has provided around A\$35 million a year for dementia research over the past few years; primarily through the National Health and Medical Research Council (NHMRC), but also through the Australian Research Council (ARC) and a range of other programs. In late 2013, the Government made a commitment to an additional A\$200 million over five years for dementia research, bringing it to a level commensurate with research funding for other major chronic diseases.

## Annex B: BANGLADESH

Estimated Number of People with Dementia ('000)			Estimated Costs of Dementia in Y2015 US\$ (mil)			
Y2015	Y2030	Y2050	Medical	Non-Medical	Informal Care	Total
460	834	2,193	\$ 86	\$ 42	\$ 193	\$ 321

*(data from ADI 10/66 Dementia Research Group)*

### Country Profile contributed by

Alzheimer Society of Bangladesh ([www.alzheimerbd.com](http://www.alzheimerbd.com))

HelpAge International, Bangladesh ([www.helpage.org/tags/bangladesh/](http://www.helpage.org/tags/bangladesh/))

Sir William Beveridge Foundation, Bangladesh ([www.beveridgefoundation.org/projects/health-social-care-bangladesh/](http://www.beveridgefoundation.org/projects/health-social-care-bangladesh/))

### Background

The Alzheimer Society of Bangladesh (ASB) is a humanitarian, non-government, non-profit voluntary organisation based in Dhaka, Bangladesh. It was established by social workers, caregivers and doctors in 2006, responding to the needs of people with dementia with a view in improving their quality of life.

In its formative years, the ASB's limited activities were conducted in Deogaon, Thakurgaon in the north of Bangladesh. The ASB was the first organisation dedicated to the welfare of people living with dementia in Bangladesh. Since its inception, the ASB has endeavoured to develop a wide range of programmes including awareness raising, education and training, rendering support and encouraging research on dementia.

The ASB was recognised for its role and the contribution in the field of dementia by Alzheimer's Disease International (ADI) who gave the ASB full membership of ADI in 2009. ASB was also registered as a Joint Stock Company in the People's Republic of Bangladesh (vide registration number -S-10583).

The ageing population is a growing concern around the world, particularly the increasing social and economic cost of the dementia epidemic. For Bangladesh, the world's eighth-largest population with more than 160 million people, the proportion of people over 60 years of age is projected to increase to 9% by 2025 and to 21% by 2050, which will increase the number of people living with dementia.

There is a low level of awareness amongst the population of Bangladesh about dementia and related disorders and there is a high level of associated stigma with the result that the care of people with dementia is often neglected in the family as well as in the community.

### New Partners and Bangladesh Dementia Action Alliance (BDAA)

The ASB recognised its own limitations and the fact that it was unable to expand its support for people with dementia across Bangladesh. It sought the support of others to achieve its objectives.

The Sir William Beveridge Foundation (SWBF) and HelpAge International in Bangladesh were organisations already active in providing support to the elderly in Bangladesh. In addition, SWBF also provided a broader service to people living with dementia.

HelpAge International helps older people to claim their rights, challenge discrimination and overcome poverty, so that they can lead dignified, secure, active and healthy lives. HelpAge has worked in Bangladesh in areas including emergency response, disaster risk reduction, older citizen monitoring, and access to rights, livelihood and a social pension. HelpAge recognised and included dementia as a health priority.

The Sir William Beveridge Foundation (SWBF) is a British charity registered in Bangladesh as an NGO working in the field of health and social care since 2007. Their flagship project is homecare for vulnerable elders in the Dhaka and Sylhet city areas. While delivering this project, SWBF was aware that some of the elderly people were affected by Alzheimer's disease or other forms of dementia. In London, SWBF signed memorandums of understanding with Alzheimer's Australia WA and Alzheimer's Disease International (ADI), in the years 2010 and 2011 respectively, agreeing to work jointly in the field of training, advocacy, awareness, research and care support, with a view to improving the quality of life of people living with dementia.

Alzheimer's Australia WA arranged to provide training and other support to SWBF Bangladesh, who devised their field programme to equip care workers to deal with dementia, raise public awareness, as well as organising advocacy and networking. SWBF also secured a grant to create broader awareness about dementia. The first two-day conference about dementia was held in Dhaka.

With the support of ADI, the three organisations – ASB, SWBF and HelpAge International Bangladesh – have come together to form the Bangladesh Dementia Action Alliance (BDAA) as a collective voice to advocate for people with dementia, influence public policy and create a national movement able to combat stigma, improve quality of care and develop community understanding and awareness of dementia.

The vision of BDAA is a dementia friendly Bangladesh and its mission is to ensure that all people with dementia,

their families and their caregivers have access to the best quality of care. Since coming together, the BDAA has formed an interim committee to manage the alliance and developed by-laws for its governance. It has also developed a business plan and appointed a coordinator to operate the secretariat.

### Number of people supported

ASB has endeavoured to raise awareness with as large a number of people as it can reach with the limited resources available to it. This has resulted in a better understanding about dementia in some parts of the country.

HelpAge has operated a number of programmes including health programmes and homecare. The number of older people who received support from the trained volunteers totalled 1,000, including people with dementia.

SWBF has been providing care to approximately 700 elderly people, of whom many are living with dementia.

### National dementia strategy/plan

Bangladesh does not have a national plan or strategies to support people with dementia. However, in November 2013, the government approved a draft national policy for the welfare of elderly people. The policy aims to protect the rights, and ensure the welfare of, elderly people, defined as those above 60 years of age.

### Awareness raising

Every year, ASB observes World Alzheimer's Day and World Alzheimer's Month. The main participants are students, social workers, caregivers, doctors and nurses. The aim is to provide information to the public about dementia and related disorders through discussions, meetings, seminars and campaigning through leaflets and posters to mark the significance of the day.

The media is engaged to propagate the views and news on dementia and related disorders, such as in newspaper articles featuring the people taking care of those with dementia. During its formative years, and until quite recently, the majority of those activities were conducted in the north of the country where ASB was formed. In the last three years some activities have also been conducted in Dhaka.

The strategic objectives of ASB include increasing awareness and understanding of dementia, advocating on behalf of people living with dementia, developing a dementia friends group (volunteers and caregivers), providing education and training, and networking with other organisations.

In HelpAge's first health strategy, it recognised that other non-communicable diseases (NCDs) increase the risk of dementia, and so it organised awareness raising events on related health issues as well as dementia.

The SWBF, with support of an international grant, planned and launched a three year Dementia Awareness

Campaign for Bangladesh. The focus of the campaign is to raise awareness at government and community levels, including health professionals. The associated eight-point plan targets various sectors in the community and endeavours to create a better environment for people living with dementia.

### Resources

Since 2010, ASB has provided a small library and resource centre at its office in Dhaka. This can be accessed by both family caregivers and the general public. ASB has also produced three newsletters called "Dementia Sangbad" and, provided resources are available, the newsletter will be produced quarterly. ASB has created a Facebook page ([www.facebook.com/alzbangladesh](http://www.facebook.com/alzbangladesh)) and its website ([www.alzheimerbd.com](http://www.alzheimerbd.com)) provides information on dementia including guidance for caregivers and research articles. Information is provided in English as well as Bengali.

BDAA has recently launched a Facebook page ([www.facebook.com/pages/Bangladesh-Dementia-Action-Alliance/546050632184346](http://www.facebook.com/pages/Bangladesh-Dementia-Action-Alliance/546050632184346)), and registered a domain name in preparation for providing a website. The web and the social networking sites are used to promote awareness about dementia and dementia care.

SWBF, together with the Daffodil International University, Dhaka, is carrying out field-level study to find out the dementia conditions amongst residents (aged 60 years and over) of Wards 15, 16 and 17 of Dhaka city (out of 90 wards in total). The results of this study will be presented in a seminar to be held later in 2014.

### Training

ASB has been able to provide limited training to caregivers and volunteers on how to best care for people with dementia. Expansion of this programme is dependent on available resources.

SWBF trained, equipped and fielded 34 volunteers in that many districts (out of 64 districts in Bangladesh) to be the flag bearers of their campaign to disseminate information on dementia.

### Services

ASB provides voluntary services through a telephone helpline and the creation of one support group run by volunteers. Use of these services is limited and only a small number of people access them. The services have been available from its Dhaka office since 2011.

HelpAge International, as part of its health service focus on NCDs, organises camps for older people. Dementia features in these.

SWBF provides care to people living with dementia in their homes, advises and trains family caregivers and advises the families of older people.

### **Government funding**

Neither ASB nor the other BDAA members receive any government funding.

### **Government spending on community services**

The National Institute of Neuroscience provides limited advice to people with dementia. Mental health care and other departments (Department of Geriatric and Organic Psychiatry and Geriatric OPD clinics) are available in the National Institute of Mental Health, Dhaka for people with dementia and for senior citizens. Bangladesh Probin Hitoishi Sangha also provides medical care services. The programmes have been created in response to the increasing awareness about dementia among health professionals.

## Annex C: CHINA, PEOPLE'S REPUBLIC OF

Estimated Number of People with Dementia ('000)			Estimated Costs of Dementia in Y2015 US\$ (mil)			
Y2015	Y2030	Y2050	Medical	Non-Medical	Informal Care	Total
10,590	18,116	32,184	\$ 9,055	\$ 4,483	\$ 31,081	\$ 44,619

*(data from ADI 10/66 Dementia Research Group)*

### Country profile contributed by

Alzheimer's Disease Chinese (ADC) ([www.adc.org.cn](http://www.adc.org.cn))

### Background

The Alzheimer's Disease Chinese (ADC) was established in 2002 by a group of medical professionals, and was later joined by social workers, family caregivers, and volunteers. The mission of ADC is to advocate for improved lives and well-being of people living with dementia, and to raise awareness of dementia among policy makers, professionals, public, and family members. Now chapters of the association have been set up in more than 25 provinces and more than 200 memory clinics are currently running nationwide.

### Number of people supported

A recent meta-analysis published in The Lancet (2013) estimated there are nearly 9.19 million people living with dementia in China. The prevalence is further expected to increase as the aging population is increasing dramatically.

### National dementia plan/strategy

China has yet to introduce a specific national dementia plan. However, promoting dementia care has been included in the National Mental Health Plan. In the National Mental Health Plan (2000-2010) dementia has been included as one of the key mental disorders among older adults. In the Mental Health Plan (2011-2020), increasing the public awareness and early detection of dementia have been listed as priorities. In recent years, the Government has placed more attention on providing quality dementia care and investment in dementia research. The National Health and Family Planning Commission (formerly Ministry of Health) has included dementia care as one of the priorities of international collaborations among health sectors with UK and France. The Ministry of Civil Affairs has included dementia care training as one of the training courses for staff and administrators of nursing homes.

### Public awareness and education

In the 12 years since ADC began, public awareness and education has always been one of the key areas of focus. The major highlights are as below:

Free public talks in different cities and districts of China to raise public awareness and to encourage early detection of dementia and mild cognitive impairment.

Leaflets and booklets on brain health and dementia for public events.

Radio interviews, newspaper, internet, and TV shows on different topics of dementia.

Series of public awareness and education programmes during World Alzheimer's Month, including press conferences on ADI's World Alzheimer Report and education fairs on World Alzheimer's Day. One of the highest impact campaigns was organized in collaboration with China CCTV in 2012, when TV shows and featured reports lasted nearly 50 days.

Regularly updating the education information on ADC's website.

Online training course on quality dementia care (co-developed with Peking University Institute of Mental Health and China Alzheimer Project 360).

### Training

ADC aims to build the capacity for quality dementia care through training and education for the general public, memory specialists, community doctors, dementia caregivers, and policy makers.

ADC has become the major organization to provide training for memory specialists. During the build-up of memory clinics throughout the nation, courses have been delivered to physicians, including neurologists, psychiatrists, and geriatricians, to improve their skills for clinical diagnosis and management of people with dementia. In addition, in collaboration with other institutions, ADC is actively involved in training for dementia case management, and education for community doctors.

With the increased need for quality dementia care, ADC has collaborated with non-government organizations and institutions to develop online training courses for dementia caregivers.

Every year, members of ADC provide education for the general public in different cities of China. More than 1,000 sessions have been delivered by 2014. In addition, public education is also conducted through newspapers, internet, TV and radio.

## Services

Although Alzheimer's Disease Chinese does not directly provide dementia services for people with dementia, ADC's members see patients at their clinics, support dementia caregivers groups, and provide routine follow-up for people with dementia. Most of the memory clinics that ADC supports provide services including screening for dementia, diagnosis, treatment, and educating the public and dementia caregivers. Publications and informative resources are delivered in these memory clinics and communities.

## Government support and funded services

Geriatricians, psychogeriatricians, psychiatrists and neurologists are providing specialist medical care services to people with dementia at memory clinics. Some of them also offer community services for screening cognitive impairment and providing counselling for dementia caregivers.

The Government has listed improving dementia care as one of the major topics on the national health aging strategy. More specific action plans are under development.

The Government encourages different stakeholders to explore different kinds of services for older adults, including dementia care. There is a great lack of well-trained professional caregivers for people with dementia. High-standard service for older adults is mostly run on a self-financing basis.

In 2014, 42 districts nationwide have been designated as the catchment of elderly care by Ministry of Civil Affairs and National Development and Reform Commission. The government allocates some budget to subsidise services for older adults. However, dementia care is not officially included. In 2014, the government invests RMB35 per person for community health service, including services for people with severe mental disorders. People with dementia who have severe psychosis may be cared for by these services. ADC will collaborate with pioneering institutions on dementia care to advocate for including dementia care in the community health service package.

## Annex D: CHINA, HONG KONG, SAR

Estimated Number of People with Dementia ('000)			Estimated Costs of Dementia in Y2015 US\$ (mil)			
Y2015	Y2030	Y2050	Medical	Non-Medical	Informal Care	Total
115	212	436	\$ 190	\$ 1,536	\$ 1,501	\$ 3,227

*(data from ADI 10/66 Dementia Research Group))*

### Country profile contributed by

Hong Kong Alzheimer’s Disease Association ([www.hkada.org.hk](http://www.hkada.org.hk))

### Background

The Hong Kong Alzheimer’s Disease Association (HKADA) was established in 1995 by a group of medical professionals, social workers and family carers with the mission to advocate for the improvement and well-being of people with dementia, offering various kinds of services, including: in-home training, centre-based service, education, training, and early detection.

18 years since HKADA began, the association is now currently operating 4 day centres to provide specialised care and therapies to people with dementia and support to their caregivers.

### Number of people supported

There is no updated national dementia prevalence study by the Hong Kong Government, however according to the 2012 population census, the number of people aged over 60 is about 1.3 million in Hong Kong. According to one of the latest studies, the prevalence of dementia in Hong Kong for people aged 60 years or above is now over 100,000 and counting. The prevalence is further expected to increase by 222%, up to over 332,000 people in less than 25 years’ time.

### National dementia plan/strategy

Although Hong Kong has yet to introduce specific national dementia plans, a number of recent dementia supportive measures have been implemented by the Government. This includes allocating HK\$200 million to a Dementia Supplement to service units to increase the number of professional staff in dementia care and implementing a pilot scheme of community care service vouchers in 2012-2013 to subsidise elders to use specialised services, including dementia services. Also, an expert group on dementia was formed in late 2013 under the Mental Health Review Tribunal of the Food and Health Bureau of the Hong Kong SAR Government to advise the government on policy initiatives. The External Vice Chairman of HKADA has been invited as one of the members.

### Training

The Institute of Alzheimer’s Education (IAE) was inaugurated in 2013. It aims to build the capacity of the entire community for better care of people with dementia

by providing training and education for the general public, professionals, and all other kinds of carers.

In line with policy direction, the need for capacity building to support people with dementia at community level has become one of the focuses of Non-Government Organisations (NGOs) and institutions. With emphasis on human resource development with a 360-degree approach, HKADA has been striving to raise the competency of professionals (including GP training, nurses, allied health professionals and social workers), semi-professionals (e.g. care workers, health workers, informal carers etc.), and any other people who may come in to contact with people with dementia (e.g. bus drivers, police, fireman, shop keepers, etc.) in the community. Since a significant number of people with dementia are currently living in residential homes, HKADA has also been active in providing specialised training to care staff and health workers working in residential settings.

In addition, HKADA has also become the pioneer of a specialised training programme for Certified Dementia Care Planners. By the end of the year 2014, approximately 120 planners will be capable of care planning and the management of people with dementia in either community or residential home settings.

### Services

Hong Kong Alzheimer’s Disease Association operates as a non-profit and self-financed organisation and provides different specialised dementia services in Hong Kong:

- Specialised dementia day centre: serving over 14,200 person-times (daily attendance of service x total number of service days) of service for people with dementia in a year, which provides cognitively stimulating activities, other non-pharmacological therapies, day respite care, in order to relieve caregivers’ stress and to maintain the quality of life and functional status of people with dementia.
- In-home training: serving about 320 person-times of service in a year, which provides individual home training to clients, caring skills training and advice to caregivers.
- Early detection services: serving about 300 people in a year, which provide detailed neuro-psychological assessment to elders with cognitive decline and refer

suspected cases for further medical follow up and specialised dementia services.

- Carer support, counselling and training to family caregivers.
- Publications and informative resources.

### Public awareness and education

Public awareness and education was one of the key focuses of HKADA in the year 2013/14, highlighted as below:-

- Free public talks in different districts of Hong Kong to arouse public awareness and to encourage early identification of the disease.
- Production of information display panels, leaflets and booth games on the disease and HKADA's services for public exhibitions/fairs.
- Publication of a quarterly newsletter with information related to the disease and stories on people with dementia and their families.
- Monthly radio interviews and newspaper features on different topics of dementia.
- Explored and sustained free promotion channels/ media for awareness and education purposes.
- Series of public awareness and education programmes during World Alzheimer's Month, including press conferences on research on the importance of early identification and ADI's World Alzheimer Report release, education fair on World Alzheimer's Day.
- Regularly updating the education information on HKADA's website and Facebook page.
- Establishment of Institute of Alzheimer's Education to provide Certified, General Practitioners training.
- Dementia Care Planner Course (co-developed with ADI) and education to students.

### Government support and funded services

Geriatricians, psychogeriatricians, psychiatrists and neurologists of the Hospital Authority are providing specialist medical care services to people with dementia at outpatient clinics. They are also offering outreach assessment and treatment services to designated residential care homes for the elderly and providing cognitive rehabilitation at day hospitals.

The Government is providing a variety of subsidised community care services and residential services within the Long Term Care system to seniors assessed to have moderate-to-severe impairment, including home care, day care, day respite, residential respite and carer support. However, these services are all operating in an integrated approach, where seniors with different healthcare needs are mixed together in one unit. Until now, all specialised services for people with dementia are being run on a self-financing basis, without government subvention.

In 2012-2013, the government allocated over HK\$200 million to a Dementia Supplement to subsidise day care centres/units and residential care homes so that they can employ additional professional staff to enhance the care for people with dementia.

## Annex E: CHINA, MACAU, SAR

Estimated Number of People with Dementia ('000)			Estimated Costs of Dementia in Y2015 US\$ (mil)			
Y2015	Y2030	Y2050	Medical	Non-Medical	Informal Care	Total
4	11	26	\$ 11	\$ 91	\$ 56	\$ 158

*(data from ADI 10/66 Dementia Research Group)*

### Country profile contributed by

Macau Alzheimer’s Disease Association ([www.mada.org.mo](http://www.mada.org.mo))

### Background

Macau Alzheimer’s Disease Association (MADA) was established in 2010 and operates with a part-time secretary.

### Number of people supported

MADA currently supports approximately 110 people with dementia and 414 caregivers.

### National dementia strategy/plan

A policy for prevention and care of older people with Alzheimer’s disease has been positioned as the priority of policy address by the Macau Government for four consecutive years. However, so far there is no national dementia plan in place.

### Organisation strategic framework

MADA was founded in the hope that through community education and proper training, the public will attain the correct understanding of dementia, resulting in positive attitudes and better control of this disease.

MADA aims to provide training courses for caregivers of people with dementia and professionals, so as to provide high quality professional care for people with dementia.

The association emphasizes early detection for people with dementia to receive timely care. MADA also promotes research on dementia.

In addition, MADA is committed to collaborate with other agencies to broaden the experience and service network, which would significantly enhance caregiver dementia care skills and enable the public to better understand people with dementia and their caregivers.

The priorities for MADA in the coming years are to run the following programmes:

- Benevolence Lights Up My Later Life: A tailored Meta-programme to address the ageing population in Macau
- The development of a training programme for informal caregivers of older people with dementia in Macau
- The development of a memory clinic for older people with dementia in Macau
- The development of a helpline service for older people with dementia in Macau

### Awareness raising

MADA organises awareness raising activities both independently as well as in collaboration with partners, through public lectures, conferences and media interviews.

#### Public lectures

Members of MADA served as keynote speakers for hosting public lectures and training workshops for the caregivers of people with dementia. Examples of these lectures are:

- The Forgotten Time – Dr Zeng Wen, Chairman
- When Parents, Family Members or Friends Live with Alzheimer’s Disease – Dr Lam Wan Mei, Vice-Chairman
- Keeping Our Brain Functioning to Slow Down Ageing: Brain Refreshing and Wisdom Strengthening Activity – Dr Pun Cam Leng, Vice-Chairman
- Effective Prevention Measures for Alzheimer’s Disease: Guides on Daily Diet and Activities – Ms Lau Gar Bo, Director
- To Recognise Alzheimer’s Disease At An Early Stage: Distinction between Normal Ageing and Alzheimer’s Disease – Dr Vai Man Chi, Vice-Chairman
- Prevention of Cognitive Impairment and Alzheimer’s Disease Begins with the Fine-tuning of Daily Habits – Ms Lei Wai In, Director

#### Conferences

1. Hosted the 21st September World Alzheimer’s Day Hong Kong-Macau Conference “Let Fiber Optics and 6-Arts Transmit Love to All”. Through interviews by the Macau broadcast media and newspapers, public awareness of dementia among the community was raised. Prof Charles Kao, a famous Nobel Prize winner living with dementia, and Mrs May-Wan Kao, honorary chairman of MADA were keynote speakers for the public lecture “Sharing experience of giving care for dementia”. Dr Zeng Wen, the Chairman of Board of Directors of MADA, was a keynote speaker for the topic “Investigating the community-dwelling of older people with dementia in Macau” to raise the public awareness of dementia through the mass media.

- Alzheimer's Disease International (ADI) and MADA co-organised the "16th Asia Pacific Regional Conference of Alzheimer's Disease International" on 14 December 2013 at the World Trade Center Macau, in collaboration with Kiang Wu Nursing College of Macau (KWNC) and Hong Kong Alzheimer's Disease Association (HKADA). The conference, themed "Capacity Building in Dementia Care", introduced the latest updates on dementia diagnosis and treatment, dementia care in Asia and the day care centre's assistance in alleviating the burden of family caregivers. On that day, more than 400 elderly care professionals including doctors, nurses, social workers, psychologists, occupational therapists and physiotherapists from 16 countries as well as Macau and the Pearl River Delta regions took part in the conference.

### Memory walk

On the day after the regional conference in December 2013, the organisers held a "Memory Walk" in which meeting delegates from Macau, the Pearl River Delta regions and various countries went on a local tour and visited some of Macau's world heritage sites such as A-Ma Temple and Lilau Square.

### Interviews by Macau broadcast media

Feb 2011 – Directors of MADA attended an interview hosted by Paul Lau at Rádio Macau

Mar 2011 – Exclusive interview on MADA with Macao Daily News

Mar 2012 – Explore social attitudes and related issues about dementia in Macau through a series of TV programmes and documentaries

### Online Quiz

MADA provided support for the project "Benevolence Lights Up My Later Life", which was organised by Kiang Wu Nursing College of Macau. There was an online quiz game under this project, the purpose was to raise public awareness, develop a positive attitude, and enhance knowledge about dementia for the Macau residents. More than 2,300 people joined the project and feedback was positive.

## Resources

### Online resources

- MADA website which provides a brief introduction to dementia ([www.mada.org.mo](http://www.mada.org.mo))
- 'Benevolence Lights Up My Later Life' public lecture's online content. All the public lecturers' PowerPoint presentations are uploaded onto the Kiang Wu Nursing College of Macau's website. ([www.kwnc.edu.mo/baba](http://www.kwnc.edu.mo/baba))

### Leaflets

- "The inaugural issue of MADA" - Introduces the principles and missions of MADA
- "Benevolence Lights Up My Later Life" - Describes the symptoms of dementia, causes, prevention possibilities, treatments and promoting the project
- "Let Fiber Optics and 6-Arts Transmit Love to All" - Shares experiences on caring, to share the research: Investigating community-dwelling older people with dementia in Macau, the effect of Chinese calligraphy on health, longevity, and happiness, and the relationship between 6 arts and a healthy brain

## Training

### For healthcare professionals - online self-study programme

"Benevolence Lights Up My Later Life" has an online self-study programme which is offered to professionals in the social welfare field. This online self-study Programme aims to introduce the definition, diagnosis and common symptoms of Alzheimer's disease. The programme also focuses on investigating the ways to take care of people with dementia with scientific methods. Throughout the programme, participants attend workshops and lectures on different topics, such as consultation on Alzheimer's disease cases, patients' self-care and thanatology (understanding end-of-life stage).

### For caregivers, domestic helpers, volunteers - caregiver training workshops

MADA's caregiver training workshops designed for the caregivers of people with dementia aims to teach skills and techniques for caring for older people and the correct attitude in treating an older person. The training workshop topics and keynote speakers from MADA are as follow:

- Practical Workshop for Dementia Care cum Visit to Organisation – Ms Ma Pui Wan, Vice-Chairman
- Care for the Person with Dementia's Family Life – Dr Leong Sok Man, Vice-Chairman
- Strategy for Activating Cerebrum: Alzheimer's Disease Exercising Tips – Dr Tam Ian Kit, Director
- A Comprehensive Manual of Community Care for Alzheimer's Disease Patients Dr Zeng Wen, Chairman and Ms Lam lok Chu, Director

## Services

MADA offers a free Alzheimer's disease service hotline (853) 2835 0001 (Monday to Friday, from 2:30p.m. to 5:30p.m.), it helps to provide a better understanding of dementia, care skills and community support services.

## Government funding within MADA

Macau Government sponsors services and activities of MADA. About 37% of costs are covered.

## Government Spending on Community Services

A policy for prevention and care of older people with Alzheimer's disease has been positioned as the priority of policy address by the Macau Government for four consecutive years. However, so far there is no specific budget for dementia care.

## Other community services

The "Benevolence Lights Up My Later Life", organised by Kiang Wu Nursing College of Macau (KWNC), co-organised by MADA, Macao Federation of Trade Unions (FAOM), General Union of Neighbourhood Associations of Macao (UGAMM) and Caritas de Macau held the development of a helpline service for informal caregivers and a day care centre for older people with dementia. KWNC set up the Memory centre and MADA provided a free Alzheimer's disease service hotline service in the Memory centre.

MADA will collaborate with KWNC, UGAMM, FAOM and Caritas de Macau, also with help from Alzheimer's Association of Hong Kong as well as Professor Henry Brodaty in Australia, and the expertise of Professor Lynn Chenoweth, to integrate their expertise into the elderly day centre in Macau, this includes: Yee Chun Day Care centre and Luk Yeung Day Care centre under UGAMM, and Longevity Special Day Care Centre under Caritas de Macau. The aim is to establish a supportive community network and a place to provide training to caregivers on a regular basis.

## Research funding

The Macau social welfare institute sponsors some Alzheimer research amounting to MOP 546,000. Some examples of research conducted by MADA with Dr Zeng Wen as the main researcher include:

- **Research title:** Investigating Community-dwelling Older People with Dementia in Macau
  - **Objectives:** To educate pupils and parents to recognise the early dementia symptoms, and detect older people with dementia at home; to assess the caring needs of the family members
- **Research title:** Burden of Informal Caregivers of Community-dwelling Older People with Dementia in Macau
  - **Objectives:** To explore the burden of informal caregivers of community-dwelling older people with dementia in Macau and to investigate the factors related to their burden
- **Research title:** The Development of a Training Programme for Informal Caregivers of Older People with Dementia in Macau
  - **Objectives:** Based on the cultural meaning of burden for informal caregivers, to develop a culturally appropriate training programme for relieving caregivers' burden
- **Research title:** The Development of Memory Clinic for Older People with Dementia in Macau
  - **Objectives:** To evaluate the cognitive assessment scales in Chinese context and to develop the memory clinic for older people with dementia in Macau

## Annex F: INDIA

Estimated Number of People with Dementia ('000)			Estimated Costs of Dementia in Y2015 US\$ (mil)			
Y2015	Y2030	Y2050	Medical	Non-Medical	Informal Care	Total
4,031	6,743	12,542	\$ 1,353	\$ 670	\$ 2,597	\$ 4,620

(data from ADI 10/66 Dementia Research Group)

### Country Profile contributed by

Alzheimer's and Related Disorders Society of India (www.ardsi.org)

### Background

Alzheimer's and Related Disorders Society of India (ARDSI) is the national Alzheimer association of India dedicated to the care, support, training and research of dementia. ARDSI has been at the forefront of improving the situation of dementia care since 1992. ARDSI has been a full member of ADI since 1993.

ARDSI has its National Office in New Delhi and its Administrative Office in Trissur, Kerala and functions through its 20 chapters across the country.

The ARDSI National Office and the five centres directly managed by it have a staff of 43 paid health and social care professionals. ARDSI's chapters across the country have around 40 paid staff and are ably supported by a total of approximately 250 volunteers.

### Number of people supported

ARDSI National Office and its chapters run services to benefit people living with dementia and their family members. The approximate annual outreach has been around 4,000 people seeking direct services and many indigent people with dementia and carers through indirect services such as talks, printed material, website, trained trainers and other services. ARDSI, since its inception and through its various chapters, has been of service to over 10,000 families.

### National dementia strategy/plan

In the years 2009-10 ARDSI made a concerted effort to bring about a Dementia India Report. Experts from the National Institute of Mental Health and Neuro Sciences (NIMHANS), All India Institute of Medical Sciences and other prominent medical institutions, service providers, caregivers, ARDSI members/ volunteers and other stakeholders contributed to this effort. This effort followed representation of experts in regional consultations and its consolidation in a national consultation. The editors of the report used the results from the consultations and the data available from the findings of the 10/66 Dementia Research Group worldwide, ADI's World Alzheimer Report 2009 and other research in India to write the report. The report was released commemorating World Alzheimer's Day on 21 September 2010. The recommendations of the report were presented to the Minister, members of the planning commission, members of the parliamentary

health committee and to the Chairperson of the National Advisory Council of India.

### Organisation strategic framework

ARDSI's vision is to create a society which is dementia friendly, dementia literate and where a person with dementia can live with dignity and honour, which he/she truly deserves.

Its mission is:

- To provide affordable, essential and easily accessible quality care and support to all those who have been affected by dementia.
- To impart training to improve the quality of life and care of people with dementia.
- To establish counselling services and family support groups.
- To bring a positive transformation in dementia care services.
- To build up a system where all those affected by dementia have access to quality care and the support they need.
- To improve public and professional awareness about dementia.
- To promote early diagnosis and intervention.

### Awareness raising

This is done primarily through public education, awareness programmes and campaigns. ARDSI offers a number of education programmes geared towards the general public, care providers, healthcare and social care professionals, and student practitioners. The public lectures, symposiums, workshops, street plays, movies, short-videos and conferences bring huge impact in dementia awareness.

Memory Walks: In connection with World Alzheimer's Month ARDSI conducts memory walks in different places. People from different walks of life join in with this event.

Social Media: ARDSI uses different social media including Facebook, LinkedIn, Google+, etc. A lot of people contact ARDSI for a variety of information connected with dementia and services and a few offer their support to ARDSI.

## Resources

ARDSI National Office and a few of its chapters have exclusive materials published in English and local regional languages for optimal outreach and sensitisation of the general public about the disease. For specific audiences seeking information, ARDSI has evolved support manuals for example a caregiver's handbook and a volunteer's manual etc. Dementia India Report is also made available through its website for public reference.

ARDSI has a dynamic online presence to disseminate up to date information on the services offered. This enables referrals and helps extend its remedial counselling through its National Dementia Helpline and its chapter centric helplines to assist people seeking information and also to reach them proactively to extend specific knowledge and provide possible assistance.

ARDSI has been part of many research projects and papers/publications are available for sharing on request to the National Office.

## Training

ARDSI National Office is recognised as a training body by the Ministry of Social Justice and Empowerment for providing training on geriatric healthcare for paramedical professionals as an advanced specialisation which is dementia inclusive. There are formal training courses of six months, one month and five day duration which includes a certificate from the respective Ministry.

Apart from this ARDSI provides many informal exclusive training sessions, especially to family caregivers and also to professional caregivers on a varied duration, based on the time available. Refresher courses are organised from time to time for family caregivers, senior citizens and people identified with early onset dementia.

In addition to this, ARDSI also provides dementia training to the professionals, student practitioners in healthcare and social care in a very cost effective manner using the existing resources and based on the needs and skills of the target groups. Recently, ARDSI has laid emphasis on creating a cadre of people who can work with us in guiding people with various dementia care and education needs (as dementia guides).

## Services

ARDSI runs across the country 6 round-the-clock residential care facilities, 10 day care centres, 25 memory clinics, 1 national and 20 regional helplines, provide domiciliary care counselling, train family caregivers, train professional care providers and also provide free medication to poor patients.

The National Dementia Helpline is well connected with the local helplines run by the chapters and various resources and services connected with them. It provides dementia advice, signposting to other services, dementia education, medical and legal intervention and a counselling service.

Caregiver Education: The caregivers of people with dementia are updated with dementia information through the helpline, monthly caregiver meetings, counselling programmes and other services.

Dementia Support Group Meeting: Dementia Support Group Meeting is conducted every month, where caregivers, senior citizens, volunteers and ARDSI staff take part.

Dementia Day Care Centre: At present ARDSI has 10 day care centres across the country. ARDSI is also well connected with other day centres run by other organisations.

Dementia Residential Care Centres: ARDSI is running 6 exclusive fulltime dementia care centres. ARDSI also has a well-established network with more age care centres extending residential care services to people with dementia.

## Government funding within ARDSI

ARDSI receives a grant from the Central Government to help conduct the training programmes in geriatric/dementia care, but that only constitutes less than 10% of the total costs per year.

## Government spending on community services

No specific allocation has been made by the Central Government for spending on dementia healthcare except a marginal provision under the scheme "Integrated Programme on Older Persons – IPOP" to set up day care centres, which has largely remained unutilised. There has been a plan to set up geriatric wards in government hospitals of 100 selected districts and efforts have been made to keep it dementia inclusive.

## Other community services

The Government has a provision to support the dementia day care centre under the Integrated Programme for Older Persons – IPOP Scheme and also conducts various training programmes in dementia care. Under the palliative care policy they also provide care to people with dementia, who need home care. As part of ARDSI's helpline work, ARDSI have identified a few hospitals and organisations which are dementia friendly to an extent in providing diagnostic services, residential care facilities, etc.

## Research funding

No specific allocation has been earmarked for research on Alzheimer's disease or other dementias. Indian Council for Medical Research-ICMR, Department of Science and Technology-DST and a few prominent medical institutions have supported sporadic research, but not in a consistent manner.

## Annex G: INDONESIA

Estimated Number of People with Dementia ('000)			Estimated Costs of Dementia in Y2015 US\$ (mil)			
Y2015	Y2030	Y2050	Medical	Non-Medical	Informal Care	Total
1,033	1,894	3,979	\$ 773	\$ 383	\$ 621	\$ 1,777

*(data from ADI 10/66 Dementia Research Group)*

### Country Profile contributed by

Alzheimer's Indonesia ([www.alzheimerindonesia.org](http://www.alzheimerindonesia.org))

### Background

Alzheimer's Indonesia is a Non-Profit Organisation that aims to improve the quality of life for people with dementia, their families and caregivers in Indonesia. Alzheimer's Indonesia, which is also known as ALZI, was established in Indonesia on August 3rd 2013. ALZI followed up on Alzheimer Assosiasi Indonesia, which was created in the year 2000 and became a member of ADI in 2009. In December 2013 it was decided to transfer the ADI membership from Alzheimer Assosiasi Indonesia to ALZI. Alzheimer's Indonesia is supported by various communities and volunteers of various ages and professionals including neurologists, psychiatrists, geriatric psychiatrists, lawyers, health communication specialists, psychologists, General Practitioners, students, etc.

### Programmes

Alzheimer's Indonesia programmes focus on:

1. Advocacy
2. Awareness raising
3. Capacity building
4. Research - development
5. Strengthening internal organisation

### Awareness raising

Various communication materials, both print and video have been produced by ALZI including the campaign themes titled "Do Not Underestimate Memory Loss", "10 Warning Signs of Alzheimer" (brochures), "Twinning Program Video Highlights", as well as others. Media penetration from the World Alzheimer's Month September 2013 campaign has reached approximately 150 million out of the 240 million population through the support of online, print, radio and TV media in Indonesia.

Since the World's Alzheimer Month Event in September 2013, Alzheimer's Indonesia has actively conducted campaigns, advocacy, and awareness raising events to increase the public's awareness of Alzheimer's disease and dementia, supported by all stakeholders including the media, elderly care communities, institutions, foundations, NGOs, private sector, international donors and the Government.

ALZI has been fostering collaboration and partnerships with DKI Jakarta Provincial Government, Ministry of Social Affairs and the Ministry of Health to proceed in declaring Jakarta as an Age and Dementia Friendly City in 2014.

ALZI has also been actively advocating for the Government to publish the Declaration and National Plan on Dementia and Healthy Ageing that is expected to be launched by September 2014 or 2015 at the latest.

### Twinning with Alzheimer Netherlands

The Twinning programme between Alzheimer's Indonesia and Alzheimer Netherlands in collaboration with Private Sector Laboratory Prodia was implemented in March 2014 in Jakarta and Yogyakarta. The programme serves as a platform for knowledge, skills and information exchange for caregivers. The event in March 2014 was attended by participants from various groups including caregivers, physicians, nurses, students, researchers, volunteers, and others.

The Alzheimer Nederland and Alzheimer Indonesia Twinning programme, supported by ADI is working on a collaboration scheme to support and deliver a Train the Trainer programme for caregivers and volunteers in Indonesia.

## Annex H: JAPAN

Estimated Number of People with Dementia ('000)			Estimated Costs of Dementia in Y2015 US\$ (mil)			
Y2015	Y2030	Y2050	Medical	Non-Medical	Informal Care	Total
3,014	4,421	5,214	\$ 6,025	\$ 48,684	\$ 38,531	\$ 93,240

(data from ADI 10/66 Dementia Research Group)

### Country profile contributed by

Alzheimer’s Association Japan (www. alzheimer.or.jp)

### Background

Alzheimer’s Association Japan (AAJ) started in Kyoto as a small peer support group of caregivers in 1980, when there was a poor understanding of dementia and no social resources for people with dementia.

AAJ has been developing year by year and taking an important role as a key body formed by family caregivers and professionals concerned about dementia care. In 2010 AAJ was certified as a public benefit corporation by the government.

In 2014, AAJ has 47 branches with 11,000 members throughout all the prefectures in Japan.

The activities are conducted nationwide by the headquarters and branches.

AAJ has eight paid staff, all of them working at the headquarters. No branches have paid staff. About 1,000 regular volunteers across Japan are managing their own branches.

### Number of people supported

In 2013, AAJ reached out to people with dementia and caregivers through:

- Monthly meetings: A total of 44,118 people with dementia and caregivers attended and exchanged information and advice. This mutual exchange involved peers and professionals.
- Telephone counselling: Headquarters had 3,323 calls and branches had 17,857 calls.
- Overnight trip for people with dementia and caregivers: 910 people with dementia and their caregivers participated.

In addition, the AAJ headquarters and branches host lectures, meetings and workshops for caregivers and professionals in cooperation with the public sector and / or professional associations.

### National dementia strategy/plan

In September 2012, the Ministry of Health, Labor, and Welfare of the Japanese national government announced a “Five-Year Plan 2013-2017 for Promotion of Measures against Dementia”, which is called the “Orange Plan”. The plan aims to change the flow of dementia care, which means a change from hospitalisation to living in

the community and a change from post crisis intervention to a proactive, preventative, early approach. Based on the national plan each local government has started its own plan. AAJ headquarters and the branches were significantly involved in the development of the plan and are now actively implementing it.

### Organisation strategic framework

#### AAJ’s mission

AAJ is committed to protecting the human rights of people with dementia and their caregivers and to pursuing the well-being of both of them through their members’ mutual cooperation and encouragement.

#### Strategic framework

1. Act from the stand point of people with dementia and their caregivers.
2. Gather together the broad ranging power of people and organisations involved in dementia care.
3. Build up cooperation with people with other diseases and disabilities.
4. Act socially through lobbying and awareness raising activities.

### Awareness raising

AAJ has been working on awareness raising on a regular basis. Most of the activities are conducted in collaboration with central and local governments, professional associations or community social welfare associations, amongst others.

- Lecture meetings.
- Publishing and distributing various types of leaflets to understand dementia and dementia care services.
- President of AAJ, Kunio Takami’s appearance and presentation on TV/radio shows more than 10 times per year.
- Special events in World Alzheimer’s Month include:
  - Street campaign, lectures and memory walks nationwide.
  - Lighting-up the landmark tower in each area in orange, which is the colour symbol of dementia care and support.

- Lobbying: AAJ has made 50 proposals and appeals for the well-being of people with dementia since 1982. The latest proposal is against the cut to Long Term Care Insurance. In May, 2014 AAJ collected 87,544 signatures against the cutbacks of Long Term Care Insurance and submitted them with the petition.
- The vice president of AAJ is a permanent committee member of the Advisory Council on Social Security of the government and advocates for people with dementia and their caregivers.

## Resources

### AAJ's resources include:

- Monthly newsletter: The number of subscribers of the headquarters newsletter is 19,000 per month and the branches' newsletter is 32,688 as of 2013. Both newsletters are distributed to members, central and local governments, aged care facilities, healthcare facilities, etc.
- Reports on the surveys conducted by AAJ: "Current condition of memory café" and "Support for people with younger onset dementia" in 2013.
- Website ([www.alzheimer.or.jp](http://www.alzheimer.or.jp)): includes information about care, education programme for children, dementia related news, list of healthcare facilities, events, and more. AAJ had 575,314 visits in 2013 and this is increasing year by year.
- Various leaflets for caregivers.
- Books.

## Training

AAJ provides training courses in cooperation with various organisations involved in dementia care. Currently the number of training sessions is increasing. AAJ's members serve in the role of lecturers as experienced caregivers and spokespeople for people with dementia and their actual caregivers.

### For professional caregivers: three regular courses (4 times per year)

1. Understanding of dementia and care
2. Medical care for people with dementia
3. Palliative and end of life care for people with dementia

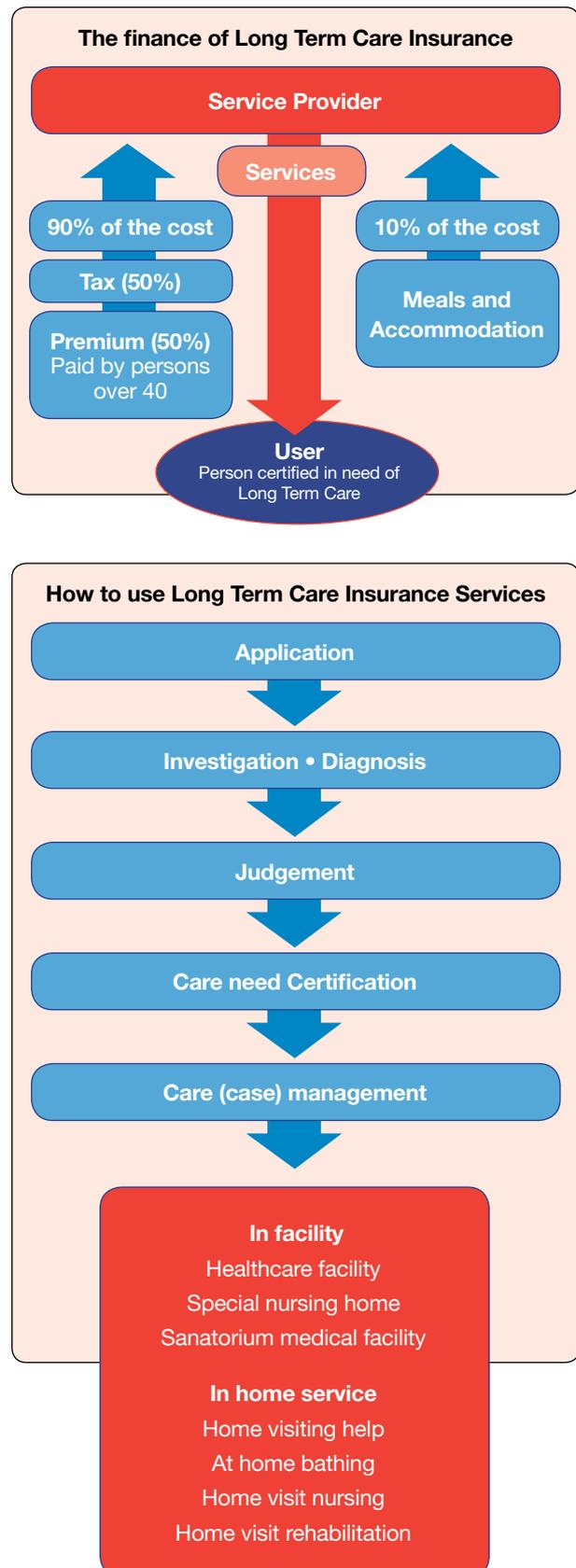
### For informal caregivers

#### Training workshop for family caregivers

1. Dementia supporter session for adults/children
2. Workshop for the telephone counsellor (monthly)
3. Workshop for the facilitators of monthly meetings (1 to 2 times per year)

Figure H.1

### Brief overview of Long Term Care Insurance in Japan



## Services in 2013

1. Telephone counselling: 3,323 calls to headquarters and 17,857 calls to all branches in 2013
2. Monthly caregivers meeting: 3,517 times in 2013 all over Japan  
 Monthly general caregivers meeting: 2,889 times all over Japan  
 Monthly male caregivers meeting: 86 times all over Japan  
 Monthly/bimonthly meeting for people with younger onset dementia: 305 times all over Japan

## Government funding within AAJ

In 2012, US\$70,000 was received for the research on the memory café project. Since April 2013, AAJ has not received any bursaries from the central government. AAJ has received some funding from Kyoto prefecture, and a few enterprises.

## Government spending on community services

Most community care services for the elderly are covered by the Long Term Care Insurance.

### Breakdown of total expenditure of Long Term Care Insurance

Community services \$40.853 billion

Multifunctional services (including both community and residential) \$8.027 billion

Residential services \$27.704 billion

**Total \$76.584 billion**

Some parts of the expenditure related to dementia are included in the expenditure of the disabled<sup>1</sup>.

## Research funding

For all types of dementia, research funding amounted to \$3.1 million (from 2012 April to 2013 March)<sup>2</sup>.

## References

1. Ministry of Health, Labour and Welfare. 24 year long-term care insurance business status report Heisei (annual report) <http://www.mhlw.go.jp/topics/kaigo/osirase/jigyoyo/12/>
2. Ministry of Health, Labour and Welfare. Website check dated 25 May 2014 <http://www.mhlw.go.jp/seisakunitsuite/bunya/hokabunya/kenkyujigyoyou/hojokin-koubou-h24/gaiyo/17.html>

## Annex I: REPUBLIC OF KOREA

Estimated Number of People with Dementia ('000)			Estimated Costs of Dementia in Y2015 US\$ (mil)			
Y2015	Y2030	Y2050	Medical	Non-Medical	Informal Care	Total
462	974	2,113	\$ 455	\$ 3,679	\$ 4,542	\$ 8,676

(data from ADI 10/66 Dementia Research Group)

### Country Profile contributed by

Alzheimer's Association Korea (www.alzza.or.kr)

### Background

Alzheimer's Association Korea (AAK) is a non-governmental organisation for dementia care, certified by the Ministry of Health and Welfare. The association, with 9 branches nationwide, is closely linked to family caregivers of people with dementia, universities, and related home care facilities. Activities include hosting events for 'Dementia Day', training dementia supporters, and running seminars on dementia. A notable achievement was the Dementia Programme which provides 24-hour care for 12,000 cases and saves 200-300 patients every year.

This year, AAK launched a research programme of home visits to 12,000 elderly living alone in the Songpa-Gu area (with a population of 600,000), and has been taking care of 1,500 elderly living alone, in collaboration with 37 live-in caregivers.

In addition, AAK makes great efforts in training professionals for early diagnosis of people with dementia and referring them to regions, so that they can be assigned to dementia care specialists at an early stage.

### Current situation of dementia in Republic of Korea

- Ageing population in Republic of Korea: 6.13 million elderly people (12.2% of total population)
- Number of people with dementia in 2013: 570,000 people (9.3% of ageing population). *Note that AAK's estimates differ slightly from the ADI 10/66 Dementia Research Group's*
- Healthcare cost per capita: 3.1 million Won (KRW) US\$ 3,000 per year
- Total social cost: 8.7 trillion Won (KRW) US\$ 8.4 billion per year
- Time spent on daily care: 6-9 hours from caregivers spending up to 19.68 million Won US\$ 19,000 annually per person with dementia

### National dementia strategy/plan

Republic of Korea has implemented several key policies in the last 10 years. The national dementia care policy revolves mainly around insurance and the 'War on Dementia'. The idea of declaring war on dementia is to tackle the issue before it gets out of control.

### Impact of "War on Dementia" Plan (launched in 2008)

- Early diagnosis of dementia increased from 3.7% in 2007 to 60% in 2012.
- Dementia care costs increased from 34% in 2007 to 70% in 2012.
- The number of dementia care professionals increased from 1,000 people in 2007 to 6,000 people in 2012.
- The number of dementia care supporters increased to 100,000 people in 2012.

The first phase of the Dementia Management Plan (2008-2010) was processed smoothly, as announced by AAK. The ramp-up of infrastructure, easing the burden of family caregivers, and training supporters for raising awareness however, did not move forward as planned.

The second phase of the plan (2011-2013) aimed to slow the advancement of dementia and to ease the burden on family caregivers. Its key tasks included expansion of home care services, improvement for long term care, building a dementia care network, family services and enactment of the Dementia Management Act.

With the introduction of 'Elderly's long-term care insurance system' in July 2008, 'National Health Insurance Corporation' became responsible for all dementia care programmes nationwide, instead of each local government in the Republic of Korea.

The 'Dementia Management Act', effective from 1 February 2012, includes implementing a comprehensive plan for dementia care every five years. The key tasks include managing dementia prevention, early diagnosis, treatment and protection, education and public awareness raising, research and development and training dementia care specialists. Also, it aims to launch the 'Central Dementia Centre' and set up a 'Dementia Counselling Centre' at each public health clinic nationwide.

After the Dementia Management Act came into effect, all of the dementia care programmes became the responsibility of the government of the Republic of Korea and the programmes are mainly implemented by the 'Central Dementia Centre'.

The third phase is the Comprehensive Plan of Dementia Care (2013-2015) which focuses on preventing dementia, improving quality of life for people with dementia and their family members, and raising awareness of dementia

at a societal level. The key tasks include early detection and prevention of dementia, tailored treatment, ramping-up infrastructure, and supporting the families of people with dementia.

The details of the plan are:

1. Early detection and prevention of dementia: provision of medical check-up for the elderly over the age of 60 at the public health clinic; provision of thorough medical check-up for 40,000 people at a cost of 1.6 billion Won in 2012
2. Tailored treatment: provision of financial support for the cost of medicine for 56,000 people at a cost of 8.2 billion Won in 2012; provision of developing a cognitive rehabilitation programme at a cost of 600 million Won in three years
3. Infrastructure development: provision of expanding beneficiaries from 24,000 patients with dementia in 2012 to 100,000 patients in 2015; provision of ramping-up the number of facilities for day and night time care, from 1,320 in 2012, aiming to add 120 facilities every year
4. Expansion of dementia specialised hospitals: provision of expanding the number from seven hospitals in 2012 to 70 hospitals in 2013
5. Central dementia centre: provision of expanding 11 provincial centres at metropolitan (regional) dementia centre; provision of expanding the enrolment of people with dementia from 32% in 2011, up to 50% in 2013, and 70% in 2015.
6. Training 4,000 professionals every year: provision of training 200 doctors, 1,000 nurses, 200 public health workers, and 2,500 health workers at the related facilities
7. Provision of supporting the family members of people with dementia and social awareness raising

#### **Key challenges:**

1. Because people with dementia are still able to lead daily lives, they are not rated as beneficiaries. Beneficiaries of this plan are mostly the aged bedridden patients.
2. Due to the lack of social services for people with dementia who are not rated as beneficiaries, most of them are hospitalised in normal elderly hospitals, rather than in dementia specialised hospitals.
3. There are an increasing number of suicide cases of family members of people with dementia due to the heavy burden of care and stress.
4. There are many cases of elderly people with dementia wandering, which lead to their disappearance.
5. Dementia care specialists are in short supply.

### **Awareness raising**

AAK conducts awareness programmes throughout the year, with particular emphasis during World Alzheimer's Month. Awareness activities include:

- Public education: dementia supporters education and symposium
- Campaigns: memorial day gathering event and memory walks
- Use of social media: providing information and materials about dementia

### **Resources**

Resources include:

- Online information through AAK's website
- Leaflets on understanding dementia, posters and other printed materials
- Books, DVDs, etc.
- Research papers

### **Training**

AAK's offerings for training cover a wide group of stakeholder groups. Training sessions include:

- Professional care training for caregivers
- Dementia supporter education for community care for volunteers
- Symposiums about various subjects related to dementia for all stakeholders

### **Services**

Through our branches across Republic of Korea, we provide services such as:

- Online and face to face counselling service
- Hotline rescue service for wandering people with dementia
- Healing programme for the family with dementia

### **Government funding within AAK**

AAK does not receive any government funding.

### **Government spending on community services and research funding**

Approximately 2.1 trillion Won US\$ 2 billion for the Long Term Care System by the national health insurance and approximately 3.1 billion Won US\$ 3 million annually on dementia research.

### **Other community services**

The national government provides services for dementia, such as home care, respite care, day care and nursing home care through the Long-Term Care system.

## Annex J: MALAYSIA

Estimated Number of People with Dementia ('000)			Estimated Costs of Dementia in Y2015 US\$ (mil)			
Y2015	Y2030	Y2050	Medical	Non-Medical	Informal Care	Total
123	261	590	\$ 260	\$ 128	\$ 317	\$ 705

(data from ADI 10/66 Dementia Research Group)

### Country Profile contributed by

Alzheimer's Disease Foundation Malaysia (www.adfm.org.my)

### Background

Alzheimer's Disease Foundation Malaysia (ADFM) was registered in August 1997. ADFM's Head office is located in Petaling Jaya, Selangor and there are 4 local chapters which are in Penang, Perak (Dementia Society Perak), Malacca and Johor (Johor Bahru Alzheimer's Disease Association or JoBADA). Another local chapter in Kota Kinabalu, Sabah, is in the process of being set up.

ADFM has a total of 24 paid staff, broken down as follow:

- ADFM Secretariat - 7 Admin Staff
- ADFM PJ Daycare Centre - 6 Nursing Staff
- Dementia Homecare Centre - 3 Admin Staff and 8 Nursing Staff

In the Dementia Society Perak, there are:

- 6 Staff - (4 full time and 2 part time staff members)
- 2 full time American Field Service (AFS) volunteers

### Number of people supported

In Petaling Jaya, the daily average in the PJ Daycare Centre is 20 to 25 people with dementia. For the Dementia Homecare Centre, there are presently 17 people with dementia resident and one person with dementia in the daycare centre.

In Perak, the numbers were as follows:

- People with dementia attended the Dementia Daycare in 2013: 1,561
- Gender Mix: Female: 848 and Male: 713
- Ethnic group mix: Chinese: 1,257, Indians: 297, Malays: 7
- Support group for caregivers: 235

ADFM provides an online resource and support to the more than 1,000 caregivers who are members of the ADFM National Caregivers Support Network which is set up for the caregiver community in Malaysia.

There are also more than 400 home caregivers (known to ADFM) who are non-members around the Federal Territory and Klang Valley.

In addition to the online or incoming call enquiries from caregivers across the country, there are those seeking help directly from the state support groups in Penang, Perak, Malacca and Johor for which there is no formal record of the numbers seeking help.

### National dementia strategy/plan

Malaysia currently does not have a national dementia plan in place.

### Organisation strategic framework

ADFM's mission is to help people with dementia and their families living in Malaysia.

This mission will be implemented through:

- Media exposure and public education forums such as talks, workshops and exhibitions
- Practical and emotional support through Alzheimer's Support Groups, a helpline and counselling services
- Guidance and training to relatives, professionals and volunteers involved in the care and treatment of people with Alzheimer's disease and other forms of dementia
- The dissemination of information and sharing of emotions and other experiences
- Through newsletters, fact sheets, publications and other resource materials
- Caregiving services and facilities like daycare centres, respite centres, nursing homes, sitting services etc.
- Reference lists of medical specialist services and facilities throughout the country
- Fundraising activities to raise funds for ADFM's planned projects and programme of activities

### Awareness raising

The ADFM National Caregivers Support Network conducts the following activities throughout the year:

- Public awareness talks/seminars
- National caregivers conference/seminar/workshop in conjunction with World Alzheimer's Day
- Memory walks to commemorate World Alzheimer's Day
- Monthly talk and sharing session for caregivers
- Organise/participate in public events and exhibitions
- Media publicity through newspapers, radio, TV and other media
- Public carers forum

## Resources

ADFM produces newsletters, posters, factsheets, printed articles, pamphlets, handbooks, video-aided training, and related information is published on the website and the online National Caregivers Support Network.

## Training

- Professional educational training programmes/ workshops for healthcare professionals/ paramedics. One of the programmes is a 3 day training workshop on “Care of People with Cognitive Impairment”
- Training programme for caregivers caring for people living with dementia, including “Care to Make a Difference”
- Training programme for foreign as well as local domestic helpers – e.g. “Essentials of Dementia Care”
- In-house training programmes for ADFM nurses – e.g. “Living with Dementia”
- Train the trainers programme for ADFM team of trainers under the ADFM National Caregivers Support Network
- Training programmes for volunteers teams under the ADFM National Caregivers Support Network

## Services

- ADFM PJ Daycare Centre
- Dementia Homecare Centre provides homecare / residential care
- Online support 24/7 by the National Caregivers Support Network
- Monthly caregivers support sharing session
- Support group services by local chapters in Penang, Perak, Malacca and Johor

In addition, the Dementia Society in Perak provides day outings for people with dementia (to museums, parks and zoos) and transport services.

## Government funding within ADFM

ADFM receives no government funding. All funds to run ADFM are obtained from fundraising activities and donations from various corporate bodies and individuals.

However, in Perak, there is some funding derived from government sources. (In 2013 the amount spent on annual staff salaries was RM 114,000.00. Funding received from the Social Welfare Department was RM 15,000.00. This is about 13% of the staff salary costs.) Perak State government paid RM 5,000.00 as a one off payment during the official launch of the Dementia Daycare Centre in Ipoh on 22nd Sept 2012.

## Other community services

- The Ministry of Health offers courses on caregiver support but there is no formal collaboration between the various government agencies and ADFM.
- At present, there are no specially designated residential care or long-term care nursing homes provided by the government for people living with dementia (apart from the geriatric wards in the major government hospitals and private hospitals which provide extended care services).
- At present, the nursing homes and community care centres managed by the private sector are for people without dementia and older adults. They do provide care to people with dementia, however the care staff are not trained to take care of people living with dementia and they do not have specific activities for them.

As part of its objectives, ADFM has been extending its training programmes to their caregivers.

ADFM (under its outreach programmes for the community):

- Conduct continuing professional education training programmes for healthcare professionals /paramedics from the private and government agencies.
- Conduct public awareness campaigns in collaboration with the government state / district agencies and private institutions.
- Are actively involved in the Ministry of Health Technical Committee for Healthcare in the Elderly as well as the Council of Ageing under the Ministry of Social Welfare.

The Perak Dementia Society has the following support:

- American Field Service (AFS) Malaysia has been sending full-time volunteers regularly.
- UniKL Royal College of Medicine Perak has adopted the Dementia Daycare as their Corporate Social Responsibility (CSR) project.
- Private Hospitals: Ipoh Specialist Hospital and Hospital Pantai Ipoh are providing free lunches for the clients attending the dementia daycare centre.

## Research funding

There are no specifically stated government funds for research in dementia. However, research grants have been awarded for some studies in dementia (basic science and clinical).

For example, in Perak, UniKL Royal College of Medicine Perak had offered a short term research grant of RM 20,000.00 to carry out a clinical trial on ‘A six month, double-blind, randomised, placebo-controlled, parallel-group study on the effect of coconut oil on cognition and behaviour in people with Alzheimer’s disease.

## Annex K: NEPAL

Estimated Number of People with Dementia ('000)			Estimated Costs of Dementia in Y2015 US\$ (mil)			
Y2015	Y2030	Y2050	Medical	Non-Medical	Informal Care	Total
78	134	285	\$ 15	\$ 8	\$ 29	\$ 52

(data from ADI 10/66 Dementia Research Group)

### Country Profile contributed by

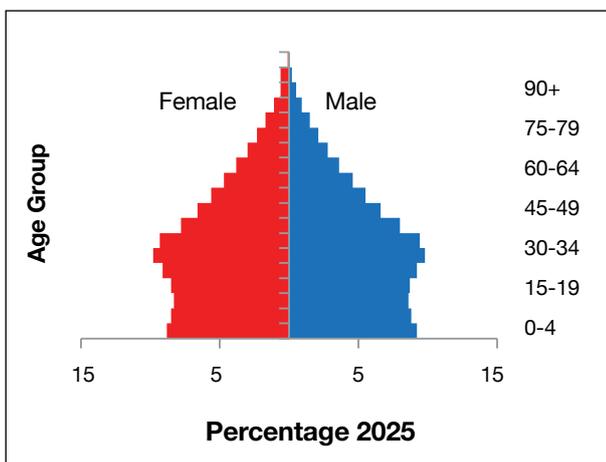
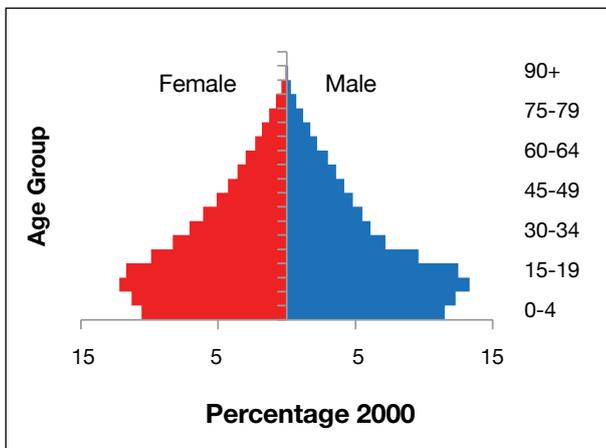
Alzheimer's and Related Dementia Society of Nepal (www.ardsnepal.org)

### Background

Alzheimer's and Related Dementia Society of Nepal (ARDSN) is a non-governmental, non-profit welfare organisation established in July 2012 mainly to raise public awareness of dementia, support people with dementia and their family caregivers, and to provide dementia training to the doctors and healthcare workers of Nepal. The elderly population has been steadily growing in Nepal. In Nepal, during the period of 1991-2001, the annual elderly population growth rate was 3.39%, compared to 2.3% of the general population. The proportion of the population 65 years and older will rise from 4.2% in 2000, to 5.8% in 2025 (Figure K.1).

Figure K.1

#### Age structure in Nepal, 2000 and 2025



(Source: NCDs Policy Brief – Nepal (2011). World Bank, South Asia)

Alzheimer's Disease International estimates that there will be 78,000 people with dementia in Nepal in 2015. These people and their families need urgent care and support. Sadly, there are very few memory diagnostic and treatment centres outside Kathmandu, and virtually no support services for the carers of people with dementia.

Nepalese doctors working in peripheral hospitals come across people with memory problems but they are unable to do much for them because of three reasons:

- **False belief:** Nepalese doctors believe that 'Dementia Management' is a specialist medical job, and therefore it's not their responsibility
- **Inadequate training:** Non-specialist doctors do not have adequate training and expertise to assess and manage people with dementia
- **Lack of local memory services:** There are no local memory clinics to carry out a comprehensive dementia assessment and to offer dementia diagnosis, devise a treatment plan, and follow-up care including support and education to family caregivers.

### National dementia strategy/plan

Nepal does not have a national dementia plan as yet. ARDSN has submitted a draft 'Nepal Dementia Care Plan' to the Ministry of Health in April 2013. The plan has the following seven objectives:

1. Advocacy and awareness raising measures
2. Human resource development for dementia care
3. Establishment of regional and zonal memory services
4. Access to affordable medication for dementia
5. Dementia care in the community
6. Inpatient care for people with dementia
7. Establish a national dementia research and training centre

There was a government change in Nepal in March 2012 which means ARDSN will have to continue lobbying the new Health Minister and other policy makers to keep dementia on their priority list.

## Awareness raising

Since its inception in July 2012, ARDSN has established itself as a national organisation by organising a number of activities to raise public and professional awareness of dementia. So far it has focused on the following activities:

- Providing forum for members to establish academic, professional, and social links with other associations or groups in similar areas of work.
- Providing advice and guidance on a national level to the government, professionals and other non-statutory bodies on issues related to Alzheimer's disease and mental health.
- Promoting issues related to public awareness programmes about dementia and help in building capacity in related fields.
- Encouraging research in dementia, conduct training and periodic CME training for mental health professionals, and training for family members and caregivers.
- Influencing government authorities through lobbying.

ARDSN has conducted several talks about dementia to members of senior citizens organisations all over Nepal, students and teachers of several schools and colleges, as well as using articles and interviews in the media. Some of the interviews are available on YouTube and the website. ARDSN has published a Dementia First Aid book in Nepalese and it is freely downloadable from the website.

## Resources

ARDSN is working closely with the Nepalese Doctors' Association UK and other national and international organisations to set up relevant research projects in Nepal.

Dr. Nidesh Sapkota has been investigating the number and proportion of people living with dementia amongst patients attending the outpatient clinic at BPK Institute of Health Sciences, Dharan. Similarly, Dr. Aditya Verma and Dr. Arun Jha have set up an epidemiological survey of dementia in Janakpur, a southeast district head quarter town. Dr. Rachana Sharma and Dr. Asish Dutta are planning to investigate the knowledge of dementia amongst recently graduated doctors. Dr. Arun Jha and his psychiatrist colleagues have already surveyed the hospital doctors about their knowledge and attitude of dementia.

## Training

ARDSN has mainly concentrated on the following activities:

1. Training paramedics such as staff nurses, health assistants, auxiliary health workers, and other primary healthcare workers.
2. Training psychiatrists and neurologists on how to run memory clinics
3. Organising training workshops for local organisations, government bodies, volunteers etc.

ARDSN has trained over 200 Nepalese doctors to pick up early signs of dementia and to refer them to specialist memory clinics. It has also conducted specialist workshops to train specialists in making an accurate diagnosis and helping people with dementia and their carers.

## Pressing issues

ARDSN is a newly established organisation in a country where awareness of dementia and healthcare resources are limited. The Department of Health is concentrating more on non-communicable diseases and has not allocated any resources for dementia care. Psychiatrists and other healthcare professionals are slowly realising the importance of dementia and they have started listening to ARDSN. Although challenges are many, we are confident of improving the situation in the next 5 years by concentrating on:

1. Research on Alzheimer's disease prevalence
2. Awareness raising of government officials and general public
3. Establishment of a dementia service centre
4. Training doctors and paramedics

## Annex L: NEW ZEALAND

Estimated Number of People with Dementia ('000)			Estimated Costs of Dementia in Y2015 US\$ (mil)			
Y2015	Y2030	Y2050	Medical	Non-Medical	Informal Care	Total
60	96	154	\$ 187	\$ 678	\$ 334	\$ 1,199

(data from ADI 10/66 Dementia Research Group)

### Country Profile contributed by

Alzheimers New Zealand ([www.alzheimers.org.nz](http://www.alzheimers.org.nz))

### Background

Alzheimers New Zealand (NZ) represents people affected by dementia at a national level. Its 21 independent and autonomous Members provide support, information, education programmes and services to their local communities throughout the country.

Alzheimers NZ's Members employ approximately 130 staff, and five staff are employed in the Wellington based national operation.

### Number of people supported

Alzheimers NZ does not have a national mechanism to collect data on the number of people that its Members provide service to and for. While each Member reports these figures to their local health authority, Alzheimers NZ has not yet established a system for the national collection of data. It hopes to start work to address this gap in 2014.

### National dementia strategy/plan

New Zealand does not have a national dementia strategy/plan. In 2013, Government released the New Zealand Framework for Dementia Care which will help people with dementia and their family/whānau to maximise their independence and wellbeing by reducing stigma and providing clear, comprehensive information and an integrated, holistic approach to dementia care and support. This will guide local health authorities in their work with primary, secondary and community health and social support services to develop clear, consistent, well-resourced and easily accessible dementia care pathways.

### Dementia: A Strategic Framework

A notable achievement for Alzheimers NZ in 2013 was the development of a strong, clear and aspirational strategic framework that not only clarifies the future direction of Alzheimers NZ, but is able to be applied by all organisations operating in the wider dementia community. This framework has been named *Dementia: A Strategic Framework*.

The aim was to provide a more comprehensive and forward-looking framework that encompassed the wider dementia community. Alzheimers NZ achieved that by adopting a collaborative approach that saw it consulting extensively with its Members and externally. To work towards its vision of 'Towards a world without dementia'

Alzheimers NZ has set the following goals, which are underpinned by a number of strategies and federation initiatives.

- A dementia friendly New Zealand
- Good brain health
- Early recognition and assessment
- Living well with dementia
- High quality services

### Awareness raising

Awareness raising is a key focus for Alzheimers NZ. In 2013 it completed the first stage of the National Dementia Awareness Campaign, a sector wide campaign aimed at increasing awareness of dementia and encouraging people to see their doctor if they were worried about dementia. This included national print and television advertising and the completion of Alzheimers NZ's first benchmark survey of dementia awareness in NZ. This survey indicated that more work is needed to increase awareness and understanding of dementia.

The 2013 awareness raising activity also included events and media activity during World Alzheimer's Month, the launch of the World Alzheimer Report 2013 and the introduction of Alzheimers NZ's first Champion of Dementia, TV personality Colin Mathura-Jeffree.

On an ongoing basis, Alzheimers NZ's awareness raising activities includes:

- **Media engagement** – proactively pitching media stories about the work of Alzheimers NZ and its Members, publicising local and international research etc., and being part of national discussions about dementia related topics;
- **Publications** – publishing and promoting its quarterly newsletter, annual report and research documents such as the NZ Dementia Economic Impact Report;
- **Online** – active engagement via Facebook, Twitter and the Alzheimers NZ website;
- **Events** - running events such as the launch of the World Alzheimer Report, its biennial conference, and participating in other events within the sector;
- **Stakeholder engagement** – engaging with the wider dementia, health and social services communities to position Alzheimers NZ as the leading organisation representing people affected by dementia in New Zealand.

Alzheimers NZ's Members also regularly conduct awareness raising activities in their local communities including Memory Walks, speaking at clubs and local events, and public education activity.

Awareness raising will continue to be a primary focus for Alzheimers NZ in 2014, with a major component being the second stage of the National Dementia Awareness Campaign, for which funding has been secured up until 2016.

## Resources

Alzheimers NZ's current suite of information resources includes fact sheets on a number of topics such as personal care, communication, wandering and nutrition plus brochures and booklets that cover a number of topics in one document. These are readily available on its website and in hard copy through its Members.

In late 2013 Alzheimers NZ started a review of its information resources, in collaboration with the wider dementia community. Through this process Alzheimers NZ will update its suite of resources to be used across the sector in support of the new NZ Framework for Dementia Care and *Dementia: A Strategic Framework*. The resources will be underpinned by the content of Alzheimer's Australia's information resources.

Alzheimers NZ will also provide and promote its own research papers such as the NZ Dementia Economic Impact Report, as well as international research and resources including World Alzheimer Reports and the Global Dementia Charter.

Alzheimers NZ's website [www.alzheimers.org.nz](http://www.alzheimers.org.nz) is an important hub of information for people affected by dementia and our stakeholders, containing our information resources, dementia related news and research as well as information and news about Alzheimers NZ and our Members' activities.

## Training

Alzheimers NZ has not historically had significant input into the training of the healthcare workforce in NZ. In 2011, it worked collaboratively with Careerforce to develop an online education unit standard that is freely available to both formal and informal carers.

This collaboration will continue throughout 2014 as the two organisations work together to roll out a "train the trainer" programme within the home and community support sector. This new initiative has received Government funding, with a projected 2,000 carers to receive the training.

## Services

Alzheimers NZ represents people affected by dementia at a national level by raising awareness of dementia, providing information and resources to the public, Government, health professionals and services by advocating for high quality services for people affected

by dementia, and by promoting research about prevention, treatment, cure and care of people affected by dementia. Alzheimers NZ maintains an up-to-date website, with the focus on providing information, resources, links to its Members and current research for people affected by dementia, health professionals and the wider NZ public. Its freephone number ensures that contact with its Members is provided free of charge to anyone who requires support.

Alzheimers NZ's 21 independent and autonomous Members provide support, information, education programmes and services to their local communities. These services include:

- Support for spouses, partners, families and friends coping with the demands of caring;
- Information and education to assist with understanding and living with a dementia diagnosis;
- Information to help cope with the financial challenges of dementia;
- Support groups and day programmes for people affected by dementia.

A number of Alzheimers NZ's Members have initiated specialised programmes within their local area. Examples include an art appreciation group called "Artzheimers" and a socialisation programme designed to provide stimulating, meaningful and culturally appropriate activities for people with dementia, and respite for their carers.

## Government funding within Alzheimers NZ

The New Zealand Government makes a contribution towards the cost of the services provided by Alzheimers NZ and its Members. The contribution amounts to around 25 percent of the cost of providing services it provides to support people affected by dementia. The balance of Alzheimers NZ's revenue comes from grants, donations and events.

## Government spending on community services

The most recent estimates we have, from the 2011 NZ Dementia Economic Impact Report, estimate the cost of residential aged care at NZ\$371.9 million, with the cost of respite and support services at NZ\$40.1 million.

Government does not collect or report financial information specifically related to dementia. The total health budget is close to NZ\$14 billion, and in 2013, around NZ\$70 million extra was allocated to dementia and aged care, including NZ\$20 million for home support services, NZ\$1.2 million for dementia related training for healthcare workers, and NZ\$2 million to support dementia awareness programmes and assistance for clinical teams in early detection of dementia.

## Community services

Government provides funding for a number of community services such as aged residential care (including specialised dementia care), aged residential respite services, day programmes, social support and home support services such as assistance with personal care and household tasks. These services are provided by a number of contracted agencies in the private and not-for-profit sector.

During the development of the New Zealand Framework for Dementia Care, it was identified that a "Navigator" role is a vital component to help people affected by dementia navigate their way through the complexities of the health and social support system by providing advice, encouraging self-management, explaining the pathway, coordinating referrals and providing a point of continuity. It is recognised that Alzheimers NZ's Members are well placed to take on this role and are well placed to be part of the overall team providing support in the community for people affected by dementia.

Given the growing healthcare challenge that dementia presents, a key component of Alzheimers NZ's advocacy strategy is to continue to push for more and better services for people affected by dementia. Alzheimers NZ will continue to collaborate with the wider dementia community, private providers, and the not-for-profit sector in order to achieve this.

## Research funding

As noted in the World Alzheimer Report 2013, investment in research about dementia is woefully inadequate, and New Zealand is no exception. Anecdotal data collected by Alzheimers NZ shows that while research into dementia is taking place within New Zealand, this is significantly lower than other health research areas, with figures suggesting that no funding was allocated to dementia research in the 2013 funding round. Approximately \$69 million was allocated to other priority health research areas.

## Annex M: PAKISTAN

Estimated Number of People with Dementia ('000)			Estimated Costs of Dementia in Y2015 US\$ (mil)			
Y2015	Y2030	Y2050	Medical	Non-Medical	Informal Care	Total
450	712	1,422	\$ 160	\$ 79	\$ 403	\$ 642

(data from ADI 10/66 Dementia Research Group)

### Country profile contributed by

Alzheimer's Pakistan (www.alz.org.pk)

### Background

Alzheimer's Pakistan is the national organisation of Alzheimer's disease and related dementias. The main objective of this non-government organisation is to work towards the welfare of people living with dementia and their caregivers. Alzheimer's Pakistan is run by volunteers from all walks of life, who have dedicated themselves to this noble cause.

The head office of Alzheimer's Pakistan is located in Lahore and has 10 paid staff members. In addition to the Lahore branch, Alzheimer's Pakistan has two more branches in the cities of Karachi and Rawalpindi.

### Number of people supported

Alzheimer's Pakistan and its branches run a number of services for people with dementia and their families. Alzheimer's Pakistan currently supports around 400 people with dementia and their caregivers through direct services like day care, home outreach services, support groups, and its telephone helpline. Moreover, thousands of people with dementia and their caregivers benefit from the indirect services like its website, information material, training, etc.

### National dementia strategy/plan

Pakistan does not have a national dementia plan in place.

### Organisation strategic framework

Alzheimer's Pakistan is the national organisation of Alzheimer's disease and related dementias. The main purpose of this non-government organisation is to work towards the welfare of people living with dementia and their caregivers. The objectives of Alzheimer's Pakistan include:

- To increase public awareness and concern for Alzheimer's disease and related disorders.
- To expand access to services, information, and optimal techniques to maximise care and support for individuals and their families.
- To train family caregivers and medical professionals.
- To eliminate Alzheimer's disease through the advancement of research and treatment.
- To enhance care and support services for individuals and their families.

- To cooperate with other organisations and institutions for the elimination, research and treatment of Alzheimer's disease and related disorders.

### Awareness raising

Awareness is one of the priority areas for Alzheimer's Pakistan. In this regard a number of awareness activities are conducted throughout the year, which includes the following:

#### Events

- Lectures at different public institutions
- Seminars, workshops and symposiums
- Exhibiting movies and short videos
- Stalls and leafletting at public places

#### World Alzheimer's Month

Every year during World Alzheimer's Month (September), a range of awareness activities are organised in different parts of the country. These activities include sports competitions, seminars, lectures, stalls, media shows, etc. Moreover a Memory Walk is also organised, which is attended by a large number of people and receives good media coverage.

#### Newsletter

A newsletter is also widely circulated that provides information on Alzheimer's disease and related dementias as well as details about Alzheimer's Pakistan activities.

#### Print and electronic media

Alzheimer's Pakistan actively works with the print and electronic media which results in published articles and several on air programmes.

#### Social media

Alzheimer's Pakistan is quite active in using social media for awareness and use social media like Facebook, SMS messages, emails, website, etc.

### Resources

Alzheimer's Pakistan has developed a range of information material targeted towards family caregivers, healthcare providers and the general public. This material is published in Urdu (National language) and English

and is disseminated through hard (printed) and soft (online/internet) forms. The information and publications includes:

- Booklet: Help for caregivers (translation ADI publication) (English & Urdu Languages)
- Booklet: Alzheimer's caregivers Guidebook (English & Urdu Languages)
- Newsletter (English Language)
- Fact Sheets (English & Urdu Languages)
- Leaflet: Is it Alzheimer's Disease? (Urdu Language)
- Leaflet: Frequently asked questions about Dementia (Urdu Language)
- Leaflet: Introduction to Dementias & Alzheimer's Pakistan (English Language)
- Website: [www.alz.org.pk](http://www.alz.org.pk) (English & Urdu Languages)

## Training

We conduct training for:

- Healthcare providers on diagnosis and management of Alzheimer's disease and related dementias.
- Caregivers are provided training on how to provide proper care to people with dementia.
- Volunteers are trained on what Alzheimer's disease and related dementias are, what services Alzheimer's Pakistan provide and how they can help in awareness raising, advocacy, outreach, services, fundraising, etc.

## Services

Alzheimer's Pakistan provides a range of services, which include:

- Help line
- Caregiver education
- Support groups
- Healthcare provider training
- Day-care service
- Home outreach services
- Awareness & Advocacy
- Information material for families
- Newsletter
- Website, Facebook

## Government funding within Alzheimer's Pakistan

Alzheimer's Pakistan does not receive funding from the government. We raise our funds through fundraising campaigns, advertisements (Newsletter) and personal donations.

## Other community services

While there are no services provided by government or community organisations, Alzheimer's Pakistan collaborates with the government and partners with psychiatry departments in different government hospitals and organises training and provides them with information material. These hospitals also refer caregivers to us for counselling and support.

In 2013, we entered into a formal Memorandum of Understanding (MOU) with Mayo Hospital Lahore, which is the largest hospital in Pakistan and have established the first dementia centre at the hospital. This dementia centre is manned by Alzheimer's Pakistan staff and is providing training, counselling and support to families, awareness raising, etc.

Alzheimer's Pakistan also collaborates with different organisations in creating awareness and providing services to families.

## Research funding

Alzheimer's Pakistan currently does not have access to research funding, although continuous efforts are being made in this regard. Alzheimer's Pakistan has developed a comprehensive dementia programme for the government, which includes substantial funds for research. These programme proposals are being submitted to different provincial governments for approval. Moreover, we constantly seek collaborations with different organisations and programmes to work on much needed dementia research.

## Annex N: PHILIPPINES

Estimated Number of People with Dementia ('000)			Estimated Costs of Dementia in Y2015 US\$ (mil)			
Y2015	Y2030	Y2050	Medical	Non-Medical	Informal Care	Total
301	568	1,149	\$ 167	\$ 83	\$ 349	\$ 599

*(data from ADI 10/66 Dementia Research Group)*

### Country profile contributed by

Alzheimer’s Disease Association of the Philippines (www.alzphilippines.com)

### Background

Alzheimer’s Disease Association of the Philippines (ADAP), established in 2000, has no paid employees but has a volunteer secretary who mans the national helpline and answers calls from 10am to 5pm on weekdays.

### National dementia strategy/plan

The focus of the Department of Health (DOH) is mainly on child and maternal healthcare with the view that the population in the Philippines is still young. Dementia is therefore not adopted as a national health priority yet and the Philippines does not have a national dementia plan.

While there are no laws that protect the rights of people with dementia, the Institute on Aging, National Institute of Health, UP-PGH Manila sought the cooperation of ADAP to establish the state of dementia care in the Philippines through a survey.

In the last Philippine Congress meeting, the House Committee on Health approved proposals to create the National Center for Geriatric Health (NCGH), which shall provide a full range of healthcare services, including primary care, wellness services and behavioural healthcare to senior citizens and other older members of the country’s population. The proposed NCGH, a government-owned-and-controlled corporation shall be established for the primary benefit of senior citizens or older people. It shall provide the following services: hospital-based services with its wards divided into dementia, long-term care, palliative care, respite care and other units as may be deemed necessary; community-based integrated geriatric health services and training for the social functioning of senior citizens and their families, utilising the multi-disciplinary team approaches; education programmes, including post-graduate training and short-term courses for medical doctors and allied medical professionals in the specialised field of geriatrics and other related fields; and programme development and research to combat diseases of old age, provide consultancy advice, technical assistance and standard setting to geriatric wards, nursing homes and residential centres for senior citizens.

### Organisation strategic framework

The vision for ADAP, the prime mover in the care of Alzheimer’s disease and related disorders, is that the Filipino people optimally address issues associated with Alzheimer’s disease and related disorders, be one with the world in continuously striving for a life that is dignified, productive, and full of hope for people with dementia and their families.

### Awareness raising

Awareness activities are generally concentrated around the National Alzheimer Awareness Week (every 3rd week of September) with outreach activities in different regions of the Philippines wherein the following activities are undertaken:

- Post-graduate course for general medical practitioners (local municipal/rural health officers and members of the local Medical Society chapters of the Philippine Medical Association) based on ADAP’s Recommendations for Diagnosis, Treatment and Prevention of Alzheimer’s Disease; corresponding CME units offered
- Post-graduate course for local nurses on dementia care
- Memory Walk done in cooperation with the local government often graced by the provincial governor or the local city/municipal mayors
- Community physical exercise after the walk
- Lay forum for senior citizens on the ABCs of dementia and tips for healthy ageing
- Social media is also used in awareness raising. Activities include:

Various articles on dementia in the leading broadsheets

- Television appearances
- Radio campaign on the fight against dementia often done during the National Alzheimer’s Awareness Week
- Website and Facebook account

## Resources

Publications such as:

- Recommendations for the Diagnosis, Treatment and Prevention of Alzheimer's Disease (AD) – first edition 2005. The second edition is planned to be published in June 2014
- Caregiver manual in English and Tagalog
- Comic book for children and teenagers - "Love Remembers... Understanding Alzheimer's Disease"
- Flyers: ABCs of Dementia in English and Tagalog
- Brochures on Alzheimer's disease – English and Tagalog
- Posters on signs of Alzheimer's disease – English with Tagalog translation
- Newsletters

## Training

1. Caregiver training program - Conducted training of family caregivers on basic dementia care and how to take care of themselves
2. Basic training for barangay health workers (lay community health workers certified by DOH) on the ABCs of dementia and dementia care
3. Basic training of local doctors and psychologists on the common screening tools for dementia (MMSE, clock-drawing test and MOCA test) in preparation for screening of selected elderly of the locality for dementia

## Services

1. Helpline: inquiries received mainly centre on: where to bring a patient with dementia; availability of home facilities for expats with dementia; availability of professional caregivers; support group
2. Caregiver Support group

## Government funding within ADAP

ADAP does not receive any direct government funding. In order to harness the government, ADAP, in its outreach programmes, partners with the local government, engaging the leadership to mobilise the people we can work with, the people we aim to target as beneficiaries of our outreach programme and to offer public venues for our activities.

## Other community services

There are different nursing homes run by government agencies, religious institutions, NGOs and private corporations. These include: Luzon Camillus MedHaven, San Lorenzo Ruiz Home for the Elderly, Kanlungan ni Maria, Mary Mother of Mercy Home for the Elderly and Abandoned Foundation, Golden Acres, Jamisola Nursing Home, Bahay Pag-ibig, St Francis Home Care Center, VISAYAS Gasa sa Gugma, Mindanao Bahay Maria, Happy Haven of Mercy.

There are also some nursing homes that have sprung up to cater to elderly foreigners who wish to retire in the Philippines but do not have any relatives in the Philippines. One such home is the Rose Princess Home 1 in Cabuyao, Laguna which caters to elderly Japanese who find living in Japan on a pension expensive.

## Annex O: SINGAPORE

Estimated Number of People with Dementia ('000)			Estimated Costs of Dementia in Y2015 US\$ (mil)			
Y2015	Y2030	Y2050	Medical	Non-Medical	Informal Care	Total
45	103	241	\$ 89	\$ 721	\$ 854	\$ 1,664

*(data from ADI 10/66 Dementia Research Group)*

### Country profile contributed by

Alzheimer’s Disease Association, Singapore (www.alz.org.sg)

### Background

Alzheimer’s Disease Association (ADA) is ADI’s partner in championing the dementia-care cause in Singapore.

Established since 1990 with a handful of staff and a modest day care centre, ADA’s 90-strong staff now runs four dementia day care centres; a caregiver support centre; a resource and training centre; and a recently-launched centre that runs a pilot project to provide simultaneous support for people with early stage dementia and respite for their family caregivers by fostering a care-sharing cooperative approach. As of March 2013, ADA has an active client base of over 400; a caregiver base of more than 1,000; close to 5,000 yearly phone enquiries, and the regular training courses have benefited thousands over the years.

### Number of people supported

Due to low Total Fertility Rate and unique socio-economic characteristics, Singapore’s native population has over the past 45 years become one of the world’s fastest ageing populations. The incidence of dementia has risen along with this trend and according to the 10/66 Dementia Research Group, the prevalence of dementia will be 45,000 in 2015, rising to 103,000 in 2030 and 241,000 by 2050.

### National dementia strategy/plan

In view of the fast-aging population and challenges of ramping up an expensive healthcare infrastructure, there is much governmental awareness of the need for an integrated approach towards eldercare in Singapore. While there is no distinct dementia management policy or national dementia plan, the dementia care sector is subsumed into the eldercare policies of the Ministry of Social and Family Development, and the Ministry of Health. The Ministry of Health has also started a National Dementia Network in Singapore, and is stepping up funding and efforts in the eldercare sector as a whole.

The Ministry of Health has appointed an Agency for Integrated Care (AIC) to oversee the ramp-up of infrastructural support, and to boost the training, development and retention of human resources in the social support sector. Because of the government’s strong commitment to prepare the nation for the

imminent “silver tsunami”, ADA’s role has come into the limelight strongly in the past five years.

### ADA Singapore’s strategic framework

In line with ADA’s mission statement of fostering dementia inclusiveness in Singapore, ADA’s core values of compassion, commitment, innovation, professionalism and integrity form the basis of its strategic framework to:

1. Provide quality dementia care and support
2. To promote research, education and training for dementia intervention and possible prevention
3. To be a voice for people with dementia and for their families
4. To be the leader in Singapore’s dementia care sector
5. To enable people with dementia (and their families) to continue to live with dignity

### ADA’s services

Being Singapore’s key non-profit welfare organisation focused on addressing the challenges of dementia (note: the organisation has no regional chapters), ADA is the go-to agency for the following:

#### Services and resources

- Provision of dementia-specific day care facilities to cope with the local demand for quality dementia care on weekdays (most voluntary organisations offer a mix of general eldercare and dementia care but ADA’s day care facilities focus only on dementia care)
- Provision of weekend dementia day care programmes to provide respite to certain groups of caregivers who are unable to provide care on some weekends
- Provision of a dementia helpline for the public to reach out to ADA and for referrals to other agencies as appropriate
- Provision of home-based intervention to handle caregiver families in crisis, and to facilitate quick evaluation for referral to various dementia and/or caregiver support services (not limited to those provided by ADA)
- Provision of eldersitting services for people with dementia

- Provision of counselling, support and training of family caregivers, and advocating the Person Centred Care approach in conjunction with established overseas institutions well known in developing person-centred care (PCC)
- Provision of a dementia resource library for caregivers, a bi-annual newsletter and e-newsletter, as well as a website ([www.alz.org.sg](http://www.alz.org.sg)) and Facebook page ([www.facebook.com/alz.org.sg](http://www.facebook.com/alz.org.sg)) to engage the public and supporters of ADA in a continual relationship

#### **Training and consultancy**

- Provision of training to professional caregivers, clinicians and healthcare professionals (train the trainers), trainees and interns, in various aspects of PCC, to bolster the quality of care in the overall eldercare landscape going forward
- Provision of training to foreign domestic workers assigned to care for people with dementia during their employment in Singapore
- Develop new training curriculum to meet emergent or existing needs in line with societal trends and imported best practices

#### **Awareness raising**

- Conducting ongoing outreach activities throughout the country in the form of pitching for media coverage, setting up exhibition booths, public education talks, symposiums and campaigns to raise awareness of dementia; dialogues with government bodies, grassroots organisations and social sector affiliates; collaborating with the Singapore Health Promotion Board and AIC
- Involvement in consultations and dialogues with government agencies for exploration of new ideas, pilot projects, research and development, volunteer management, public education, funding and fund raising
- Nurturing of brand presence, corporate image and public rapport through social media platforms, web properties and campaigns, strategic alliances with social sector agencies, educational institutions, donor relationship management, volunteer relationship management

### **Government spending and funding**

As of March 2014, the Singapore Government has unveiled a budget that is targeted at the 450,000 post-65-year-old citizens (known as the “pioneer generation”) that requires assistance with healthcare needs. The S\$9 billion Pioneer Generation Fund seeks to aid long-term financing in medical insurance, inpatient/outpatient costs, specialist treatments, disability assistance and other old-age concerns. The direct impact of the Pioneer Generation Fund on dementia-care would be to reduce the strain on the needy elderly with dementia; their family caregivers, and generally avail them to more management options depending on merit.

### **Funded community services**

The current supportive eldercare climate in Singapore is realised mainly in the form of direct and indirect government subsidies for community services provided to residents, such as nursing homes and social support services. These subsidies are provided on a sliding scale determined by a limited form of means testing. Residents can also rely on the Medisave and Medishield portions of the social security funds administered by the government. Where more financial assistance is required, various avenues of appeal, such as Medifund and an upcoming MediShield Life insurance plan, are available.

At the organisational-level, funding of NGOs and Voluntary Welfare Organizations by the government is available on an adhoc, project-by-project basis, depending on merit of new initiatives and pilot projects. This could range from full funding to partial funding. Administrative costs of HQ operations are usually not separately funded. There is currently a strong governmental focus on promoting voluntarism and corporate philanthropy.

### **Research funding**

At the research level, dementia-specific studies done at university hospitals and the National Neuroscience Institute can enjoy grants by merit; private research institutes and healthcare organisations are also eligible to apply for grants on an adhoc basis.

## Annex P: SRI LANKA

Estimated Number of People with Dementia ('000)			Estimated Costs of Dementia in Y2015 US\$ (mil)			
Y2015	Y2030	Y2050	Medical	Non-Medical	Informal Care	Total
147	262	463	\$ 99	\$ 49	\$ 82	\$ 230

(data from ADI 10/66 Dementia Research Group))

### Country profile contributed by

Lanka Alzheimer's Foundation (www.alzlanka.org)

### Background

Lanka Alzheimer's Foundation (LAF) was established in 2001. Based in Colombo, LAF operates with 3 full-time paid staff.

### Number of people supported

Due to the diversity of activities and projects offered by LAF, it cannot be precise in terms of numbers of people with dementia and their carers that are helped and supported by the organisation on an annual basis. However, LAF can say that in 2013 (approximate figures):

- 50 people living with dementia attended/attend the Activity Centre on a weekly basis since the opening in January 2012
- Via several awareness campaigns facilitated throughout the year, LAF had direct contact with an audience of 4,850 in a caring role, or with an interest on this topic and the work they offer
- 68 people attended its periodical memory screening day, facilitated by volunteer doctors since September 2013
- Via the phone helpline and email, some 395 calls were taken, often from carers and relatives based in other parts of the island rather than in Colombo.

LAF also believe that the help and support they offer is extended to those who access their website and read their leaflets or any other form of information material they produce. Although these figures are difficult to quantify, LAF know that their website had a total number of 286 hits for the period of September 2013 until January 2014.

As the main office is based in Colombo, most of those accessing the service are based in and around the capital. One of the aims in the future is to explore new ways of reaching out to those who are further afield.

### Strategic framework

LAF's mission is to improve the quality of life of those with Alzheimer's disease and related dementias and enhance the well-being of their families and carers.

### Awareness raising

LAF conducts an array of activities throughout the year, some of the most important include:

- A 5km Annual Memory Walk, held in Colombo around the 21st of September to celebrate World Alzheimer's Day. The inaugural Walk was held in 2003.
- Awareness and public education programmes: open-day campaigns reaching out to all religious communities (Buddhists, Hindus, Muslims and Catholics)
- Workshops for health professionals and those in a caring role
- Circulation of a quarterly newsletter to friends of LAF
- Publication of newspaper articles and interviews by the print media (e.g. <http://www.ceylontoday.lk/35-13894-news-detail-dementia-overcoming-stigma.html> and <http://www.sundaytimes.lk/130908/plus/remember-we-can-all-become-victims-of-alzheimers-60948.html>)
- Fundraising events, including annual Christmas campaign, annual scrabble bash, musical concerts, sale of raffle tickets etc.

### Resources

Over the past two years LAF has made significant investments in the production of an array of information material for the general public as well as those with a professional and personal interest in dementia. In most cases, these have been translated into Sri Lanka's three official languages – Sinhala, Tamil and English, and are on offer in both hard copy and online, free of charge.

Some of LAF's resource materials and publications include:

- LAF's web page, recently re-vamped and with updated information on dementia care: [www.alzlanka.org](http://www.alzlanka.org)
- "What is dementia" leaflet (in all three languages)
- "Activities at home" leaflet (in all three languages)
- "Action on dementia" leaflet (in all three languages)
- LAF's Annual Report

- LAF's Quarterly Newsletter (latest news on dementia care in Sri Lanka and around the world, LAF's programmes, initiatives, opinion articles, etc.)
- General Assessment Manual (guidance for health professionals and others, in Sinhala and English, on how to assess the needs of those experiencing cognitive impairment and their relatives)

## Training

LAF's training programmes and related activities are designed to reach a wide audience, and aim to meet the needs of those with a health professional background, and those in an informal yet vital caring role.

Although we hope to improve and extend our range of training initiatives, we have so far been able to facilitate and collaborate in different programmes including:

### Health professionals

- Temporary placement programmes at our Activity Centre for occupational therapy degree students from the University of Kelania.
- Facilitate an introductory one-day a month programme on the care needs of people with dementia to final year medical students from the University of Kelania.
- Conduct periodical workshops on topics related to specific care needs of people with dementia and their relatives (e.g. workshop on facilitation of cognitive stimulation groups, and on palliative care and pain management).
- Produce guiding materials such as the Assessment Manual above referred, and of use to health professionals working in both inpatient and community based settings.
- Invite health professionals (local and overseas doctors, nurses, psychologists, occupational therapists, etc.) to volunteer with the Foundation and share skills and knowledge with our clinical community with an interest in dementia care.

### Informal carers

- Despite the professional format in which some of the workshops above described are facilitated, to invite those with no health care training yet in caring positions (paid or unpaid) to attend these programmes.
- Offer training and advice to carers and relatives and in particular to those based outside Colombo both over the phone and/or via email.
- Encourage paid and unpaid carers and relatives to visit our Activity Centre on days when activities for those living with dementia are facilitated, and to seek advice and support from our experienced work force of volunteers.
- Offer all who decide to join LAF as volunteers or paid staff an introductory induction on the work of the Foundation and above all on dementia and the care and support needs of those affected.

## Services

LAF's main services currently provided to our community include:

- **Phone helpline** and online support (via email), used to provide information and advice on dementia, counselling to those in crisis, and signposting particularly to those based in more remote parts of the country.
- **Social groups and cognitive stimulation therapy**, provided to people living with dementia and their relatives at the Activity Centre on a weekly basis. On both Mondays and Wednesdays a series of different activities, from art therapy to music, dance and exercise, creative writing, cooking and gardening are facilitated by staff and volunteers, and offered in a warm, non-threatening environment to all wishing to join. Activities are offered on a rotational basis and according to the preferences of those attending the centre.
- **Caregivers' support group**, offering an opportunity to those in a caregiving role to share their experiences and frustrations with those in similar roles.
- **Training and educational programmes** in the form of higher education support, workshops and direct one-to-one advice (as previously explained).
- **Memory screening and general psychosocial assessments** to those who are unable to access specialist medical care and seek support in understanding changes to their memory and general cognitive abilities.
- **Awareness campaigns**, with a strong emphasis on fighting the stigma around dementia and mental illness which prevails in Sri Lankan society, and on raising awareness amongst policy makers on the importance of developing health and social services suitable to meet the needs of those affected by this condition.
- **Hygiene products**, sold at the Activity Centre at a lower rate to that found on the high street, and as a way of reducing the costs associated to the day-to-day care of someone living with dementia.

## Government funding within LAF

All funding is raised in Sri Lanka, through periodical fundraising campaigns aimed at the general public and private sector, as well as private donors. LAF receives no government or international funds.

## Government spending on community services

LAF does not have access to these figures. Dementia remains a relatively unknown subject to many in Sri Lanka, hence the work in raising awareness amongst the general public and policy makers is so important.

Care of the elderly and of those with cognitive problems and with a diagnosis of dementia is done mainly in hospitals. The number of beds allocated in state run

hospitals to those affected by dementia is however limited. The National Institute of Mental Health (Colombo), Sri Lanka's largest mental health hospital, has both male and female inpatient wards dedicated to those aged 65 years and above, and presenting with cognitive decline as well as an array of different mental health related problems. Similar wards are found in other parts of the country, yet the number of beds is insufficient, and elderly patients often share inpatient quarters with patients of other age groups.

LAF is interested in working collaboratively with hospitals and other health providers, and to explore new ways of supporting people living with dementia prior and after receiving inpatient care.

### **Other community services**

Formal community care for those experiencing dementia is patchy and non-existent in most provinces of Sri Lanka. Although efforts are being made to improve specialist support to those affected by this condition, most care is still provided under statutory hospitals rather than in the community.

In Sri Lanka religious orders of different faiths have a paramount role in supporting communities afflicted by ill health – support in the form of food provision, transport, basic healthcare and shelter. The small number of residential and nursing homes for the elderly is therefore mostly in the hands of the non-governmental sector and religious orders. There are as well a growing number of privately owned residential homes, yet these are unaffordable to a significant proportion of the population.

LAF is very interested in working collaboratively with the government, religious orders and other non-governmental organisations in improving such services and to contribute in a sustainable way to the development of effective community services to those affected by dementia.

### **Research funding**

LAF is unaware of any specific government funding programmes running in Sri Lanka at present. Despite LAF's limited financial resources, the skilled and dedicated workforce will always be open to work collaboratively in any reliable and evidence-based research programme aimed at both understanding the morbidity and needs of those affected by dementia in Sri Lanka, and improving the quality of health and social care currently on offer in the country.

## Annex Q: TADA CHINESE TAIPEI

Estimated Number of People with Dementia ('000)			Estimated Costs of Dementia in Y2015 US\$ (mil)			
Y2015	Y2030	Y2050	Medical	Non-Medical	Informal Care	Total
260	461	840	\$ 412	\$ 3,326	\$ 3,252	\$ 6,990

(data from ADI 10/66 Dementia Research Group)

### Country Profile contributed by

Taiwan Alzheimer's Disease Association (www.tada2002.org.tw)

### Background

Taiwan Alzheimer's Disease Association (TADA) was founded in 2002 and is based in Taipei. TADA had the honour of hosting the ADI Asia-Pacific Regional Conference in 2008 and the 28th International Conference of ADI in 2013.

At the end of March 2014, TADA relocated its office to expand its services and functions. With 20 paid staff, TADA organises campaigns to raise awareness and provide information, delivers training, carries out advocacy work, provides social support services and organises the School of Wisdom and Family of Wisdom for people with dementia as well as their carers. TADA has provided a toll-free helpline service since 2002, and set up a 24-hour helpline in September 2014.

### Number of people supported

TADA has collaborated with local Alzheimer associations and related organisations to raise awareness and advocate for a national dementia policy. The prevalence of dementia as of 2013 is around 230,000, yet there is still a great proportion of undiagnosed cases that efforts need to be focused on.

### National dementia strategy/plan

After the 28th ADI conference in Taipei, the Ministry of Health and Welfare (MOHW) issued a national dementia plan in August 2013 and the action plan is being worked on now. The goals of the national dementia plan are (1) timely diagnosis, early treatment and risk reduction; (2) quality services for people with dementia and their carers to improve dignity and quality of life. The strategies of the plan are:

1. Raise public awareness of dementia prevention and care
2. Establish a comprehensive community care network
3. Strengthen primary prevention and healthcare services
4. Develop human resources and enhance professional competence
5. Strengthen interdepartmental cooperation and resource integration
6. Encourage dementia research and international cooperation
7. Protect rights

### TADA's strategic framework

The vision of TADA is the reduction of the incidence of dementia and an improved quality of life for people with dementia and their families who should live in a dementia friendly community. The strategies are:

1. Improving advocacy and empowering consumers
2. Increasing the awareness and understanding of dementia
3. Increasing accessible, affordable quality dementia care
4. Applying effective strategies for preventing dementia

#### Improving advocacy and empowering consumers

Involving people with dementia and their carers in the process of policy formation and advocacy

Achievements in advocacy:

1. National dementia policy was launched in August 2013
2. Early intervention projects for people with mild dementia became a priority for subsidies
3. Long-term care included dementia care
4. Assistive technology subsidy for people with dementia
5. Improvement of medication reimbursement for people with dementia in health insurance

#### Increasing the awareness and understanding of dementia

##### Media engagement

TADA's contact with the media is on an ongoing basis including responses to dementia related news and running press conferences with the launch of the World Alzheimer Reports, annual conference and World Alzheimer's Month campaign. TADA produces mini-films to raise awareness and promote dementia friendly stores.

##### Information

TADA provides information via its website, Facebook, publications and helpline. The content includes a variety of information including information about dementia, dementia care, social and care resources, patients and carer rights. TADA publishes a newsletter and care book series as well as other publications.

## Events

TADA hosts World Alzheimer's Month campaigns nationally with more than thirty local dementia associations and related organisations. TADA hosts an annual conference with societies or associations of medicine, nursing, social work, psychology and occupational therapy, etc.

## Dementia friendly stores

In 2013 TADA worked with Rotary International to initiate a dementia friendly store and keep connecting enterprises of chain stores to build a dementia friendly network nationally.

## Training

TADA delivers training for formal and informal carers. Since 2008, TADA has especially focused on the training of facilitators of the School of Wisdom, including workshops on cognitive stimulation, reminiscence therapy, art therapy, music therapy and exercise.

## Delivering services for people with dementia and their carers nationally

1. 24 hour toll-free helpline (national helpline)
2. Carer support services
  - Dementia Social Support Center
  - Always Remember You Café in six cities
  - Family of Wisdom in two cities
3. Programs for people with mild dementia
  - School of Wisdom in all cities
4. Programs for younger-onset dementia and their carers
  - Weekend leisure activities
  - Educational support groups in three cities

## Applying effective strategies for preventing dementia

Golden Age Project was designed for people over 50 years old to reduce the risk of dementia. The project included lectures, exercise classes, practical nutrition classes and outings. The feedback from the attendees was very positive. TADA is looking for funding to continue the project.

## Government funding

TADA applies for government funding every year. The funds partially cover services, events, research, conferences and training. Government funding strongly supported ADI's regional conference in 2008 and the international conference in 2013. The balance of TADA's revenue comes from private sector grants and donations.

## Research funding

Current research funding on dementia related issues is still insufficient. TADA was granted a 3-year national prevalence survey grant from the Ministry of Health and Welfare from 2011 to 2013.

## Annex R: THAILAND

Estimated Number of People with Dementia ('000)			Estimated Costs of Dementia in Y2015 US\$ (mil)			
Y2015	Y2030	Y2050	Medical	Non-Medical	Informal Care	Total
600	1,117	2,077	\$ 89	\$ 721	\$ 854	\$ 1,664

(data from ADI 10/66 Dementia Research Group)

### Country Profile contributed by

Alzheimer's Disease and Related Disorders Association-Thailand (www.azthai.org)

### Background

The Alzheimer's Disease and Related Disorders Association-Thailand (ARDA-T) represents people with dementia and their caregivers at a national level.

ARDA-T was founded in July 1996 by a group of healthcare professionals and the family members of a person with dementia. It was first established as an informal group of people with a common interest, becoming a legal association in November 1998.

Since then ARDA-T has become stronger by recruiting a network of organisations throughout Thailand. Currently there is one main organisation located in Bangkok with other networks in northern, north eastern and southern parts of Thailand. Each network works independently to provide support, information, education programmes and services to their local communities. The organisation has one employed staff member. The rest of the staff and committees are volunteers.

### Number of people supported

ARDA-T does not yet have a national mechanism to collect data on the number or type of people that the main organisation and networks provide service to.

### National dementia strategy/plan

Thailand does not have a national dementia strategy/plan. The aim is to start work to address this gap in 2014. The work through local communities has helped people with dementia and their caregivers to maximise their independence and wellbeing by reducing stigma and providing clear, comprehensive information and an integrated, holistic approach to dementia care and support. However, with the current political instability and without a national dementia strategy/plan, it is impossible to develop clear, consistent, well-resourced and easily accessible dementia care pathways.

### Awareness raising

Raising public awareness is one of ARDA-T's strategic plans since the establishment of the association. On an ongoing basis, awareness raising activities include:

- **Media engagement** – proactively pitching media stories about the work of ARDA-T and its Members, publicising local and international research etc., and being part of national discussions about dementia related topics

- **Publications** – publishing and promoting knowledge booklets, a quarterly newsletter and an annual report
- **Online** – active engagement via our website
- **Events** - running events such as World Alzheimer's Month, an annual conference, and participating in other events within the sector
- **Stakeholder engagement** – engaging with the wider dementia, health and social services communities to position the association as the leading organisation representing people affected by dementia in Thailand.

### Resources

The current suite of information resources includes brochures and booklets that cover a number of topics such as being a caregiver for people with dementia, Alzheimer's disease knowledge, healthy brain techniques etc. These are readily available on the website and in hard copy through the Members.

The website www.azthai.org is an important hub of information for people affected by dementia and for stakeholders. It contains information resources, dementia related news and research as well as information and news about ARDA-T and Members' activities. ARDA-T also provides and promotes international research and resources including the World Alzheimer Reports and the Global Dementia Charter.

### Training

ARDA-T has had significant input into the training of the healthcare workforce in Thailand. It usually has two types of training workshops/conferences annually. One is for healthcare professionals and the other for family caregivers.

### Services

ARDA-T provides public services by holding monthly support group sessions for caregivers and family members of people with dementia. The hotline phone numbers are available to ensure access to anyone who requires support for people with dementia urgently.

A number of networks have initiated specialised programs within their local area to provide stimulating, meaningful and culturally appropriate activities for people with dementia, and respite for their caregivers.



## **Alzheimer's Disease International**

### **About ADI**

Alzheimer's Disease International (ADI) is the international federation of more than 80 Alzheimer associations throughout the world. Each of our members is a non-profit Alzheimer association supporting people with dementia and their families.

ADI's vision is an improved quality of life for people with dementia and their families throughout the world. ADI aims to make dementia a global health priority, to build and strengthen Alzheimer associations, and to raise awareness about dementia worldwide. Stronger Alzheimer associations are better able to meet the needs of people with dementia and their carers.

### **What we do**

- Support the development and activities of our member associations around the world.
- Encourage the creation of new Alzheimer associations in countries where there is no organisation.
- Bring Alzheimer organisations together to share and learn from each other.
- Raise public and political awareness of dementia.
- Stimulate research into the prevalence and impact of Alzheimer's disease and dementia around the world.
- Represent people with dementia and families in international platforms at the UN and WHO.

### **Key activities**

- Raising global awareness through World Alzheimer's Month™ (September every year).
- Providing Alzheimer associations with training in running a non-profit organisation through our Alzheimer University programme.
- Hosting an international conference where staff and volunteers from Alzheimer associations meet each other as well as medical and care professionals, researchers, people with dementia and their carers.
- Disseminating reliable and accurate information through our website and publications.
- Supporting the 10/66 Dementia Research Group's work on the prevalence and impact of dementia in developing countries.
- Supporting global advocacy by providing facts and figures about dementia and monitoring as well as influencing dementia policies.

ADI is based in London and is registered as a non-profit organization in the USA. ADI was founded in 1984 and has been in official relations with the World Health Organization since 1996 and has had consultative status with the UN since 2012. You can find out more about ADI at [www.alz.co.uk](http://www.alz.co.uk).

Alzheimer's Disease International:  
The International Federation  
of Alzheimer's Disease and  
Related Disorders Societies, Inc.  
is incorporated in Illinois, USA,  
and is a 501(c)(3) 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)



**Alzheimer's Disease  
International**