FOREWORD

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

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

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

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

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

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

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EXECUTIVE SUMMARY

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

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

The report:

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

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

The report was funded by the Tsao Foundation and ADI.

The facts

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

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

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

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

The number of those with dementia will increase in the Asia Pacific region from 13.7 million people in 2005 to 64.6 million by 2050.
The number of new cases of dementia in the region is projected to increase from 4.3 million new cases per year in 2005 to 19.7 million new cases by 2050.

Different studies give slightly different results depending on their methodology. But the dementia epidemic is a certainty because the numbers of people with dementia increase with an ageing population. And those aged over 60 in the Asia Pacific will increase from under 10% today to 25% of the total population by 2050 and those over 80 years from 1% to 5% of the population.
Apart from the increase in numbers of people with dementia there are other factors that will exacerbate the social and economic impact of dementia. These include urbanisation, trends away from extended families and towards nuclear families, and the increasing number of elderly people who thus live alone. The ability to care for these people will depend on a mix of formal and informal care giving. Many countries in the Asia Pacific region may not be well prepared to provide quality health and care services for people with dementia and their family care givers.

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

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

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

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

**The Challenge**

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

- Limited awareness of dementia and in many countries a cultural context that denies its existence or attaches stigma to the condition.
- An assumption that dementia is a natural part of ageing and not a result of disease.
- Inadequate human and financial resources to meet care needs and limited policy on dementia care.
- High rates of institutionalisation in cities in some countries and lack of facilities in other regions.
- Inadequate training for professional care givers and a lack of support for family care givers.
There is much sound advice about how to meet these challenges. The tragedy for people with dementia and their family and care givers in the Asia Pacific will be if this advice is not put into practice.

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

Secondly, an action plan for dementia based on the “minimum actions required for the care of people with dementia” was presented at the 20th International Conference of Alzheimer’s Disease International in 2004 in Japan – the Kyoto Declaration (attached).

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

**Recommendations**

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

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

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

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

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

It is recommended that all Asia Pacific Governments:

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

Make provision for special needs, including people with younger onset dementia, and people with behavioural and psychological symptoms of dementia (BPSD).

3 Promote investment in research for cause, prevention and quality dementia care.

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

Access Economics
21 September 2006
**KYOTO DECLARATION: MINIMUM ACTIONS REQUIRED FOR THE CARE OF PEOPLE WITH DEMENTIA**

<table>
<thead>
<tr>
<th>Ten overall recommendations</th>
<th>Scenario A Low level of resources</th>
<th>Scenario B Medium level of resources</th>
<th>Scenario C High level of resources</th>
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<tbody>
<tr>
<td>1. Provide treatment in primary care</td>
<td>Recognise dementia care as a component of primary health care. Include the recognition and treatment of dementia in training curricula of all health personnel. Provide refresher training to primary care physicians (at least 50% coverage in 5 years).</td>
<td>Develop locally relevant training materials. Provide refresher training to primary care physicians (100% coverage in 5 years).</td>
<td>Improve effectiveness of management of dementia in primary health care. Improve referral patterns.</td>
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<td>2. Make appropriate treatments available</td>
<td>Increase availability of essential drugs for the treatment of dementia and associated psychological and behavioural symptoms. Develop and evaluate basic educational and training interventions for care givers.</td>
<td>Ensure availability of essential drugs in all health care settings. Make effective care giver interventions generally available.</td>
<td>Provide easier access to newer drugs (eg anticholinesterase agents) under public or private treatment plans.</td>
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<td>3. Give care in the community</td>
<td>Establish the principle that people with dementia are best assessed and treated in their own homes. Develop and promote standard needs assessments for use in primary and secondary care. Initiate pilot projects on development of multidisciplinary community care teams, day care and short term respite. Move people with dementia out of inappropriate institutional settings.</td>
<td>Initiate pilot projects on integration of dementia care with general health care. Provide community care facilities (at least 50% coverage with multi-disciplinary community teams, day care, respite and inpatient units for acute assessment and treatment). According to need, encourage the development of residential and nursing home facilities, including regulatory framework and system for staff training and accreditation.</td>
<td>Develop alternative residential facilities. Provide community care facilities (100% coverage). Give individualised care in the community to people with dementia.</td>
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<td>4. Educate the public</td>
<td>Promote public campaigns against stigma and discrimination. Support nongovernmental organisations in public education.</td>
<td>Use the mass media to promote awareness of dementia, foster positive attitudes, and help prevent cognitive impairment and dementia.</td>
<td>Launch public campaigns for early help-seeking, recognition and appropriate management of dementia.</td>
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<td>5. Involve communities, families and consumers</td>
<td>Support the formation of self-help groups. Fund schemes for nongovernmental organisations.</td>
<td>Ensure representation of communities, families, and consumers in policy-making, service development and implementation.</td>
<td>Foster advocacy initiatives.</td>
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<td>6. Establish national policies, programs and legislation</td>
<td>Revise legislation based on current knowledge and human rights considerations. Formulate dementia care programs and policies. - Legal framework to support and protect those with impaired mental capacity - Inclusion of people with dementia in disability benefit schemes - Inclusion of care givers in compensatory benefit schemes. Establish health and social care budgets for older persons.</td>
<td>Implement dementia care policies at national and subnational levels. Establish health and social care budgets for dementia care. Increase the budget for mental health care.</td>
<td>Ensure fairness in access to primary and secondary health care services, and to social welfare programs and benefits.</td>
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<td>7. Develop human resources</td>
<td>Train primary health care workers. Initiate higher professional training programs for doctors and nurses in old age psychiatry and medicine. Develop training and resource centres.</td>
<td>Create a network of national training centres for physicians, psychiatrists, nurses, psychologists and social workers.</td>
<td>Train specialists in advanced treatment skills.</td>
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<td>8. Link with other sectors</td>
<td>Initiate community, school and workplace dementia awareness programs. Encourage the activities of nongovernmental organisations.</td>
<td>Strengthen community programs.</td>
<td>Occupational health services for people with early dementia. Provide special facilities in the workplace for care givers of people with dementia. Initiate evidence-based mental health promotion programs in collaboration with other sectors.</td>
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<td>10. Support more research</td>
<td>Conduct studies in primary health care settings on the prevalence, course, outcome and impact of dementia in the community.</td>
<td>Institute effectiveness and cost-effectiveness studies for community management of dementia.</td>
<td>Extend research on the causes of dementia. Carry out research on service delivery. Investigate evidence on the prevention of dementia.</td>
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