

First Asia Pacific Alzheimer University

Facing challenges together

Twelve Alzheimer associations from the Asia Pacific region met in Singapore in May for training on strategic advocacy and coping with organisational growth. The training developed the skills of participants to help them run more effective Alzheimer associations.

The 35-strong group spent the first day considering strategies for managing growth. The training began with an exercise in which participants got to know each other and their expectations from the event. They hoped for 'shared knowledge and mutual help' and for 'ways to motivate staff'. The trainer from Singapore combined theory and practical information exchange, with case studies providing tangible examples of organisational structure and how associations have lobbied their governments.

On the first day, Frank Schaper outlined Alzheimer's Australia's federal structure and Socorro Martinez examined ways of meeting diverse needs in the Philippines. Key areas covered included definition of mission and vision, organisational culture and maximising capacity. Each association carried out an organisational 'health check' – an opportunity to take a step back and assess their situation. One participant commented, 'So often it feels like we're 'fire fighting'. There's never time to think "where are we?" and "where do we want to be?"'

Getting dementia onto government agendas is increasingly important



Michelle McGrath, Australia and Chang Min Choi and Sung Hee Lee, Korea, listen attentively

for Alzheimer associations. Policymakers need to be lobbied so that they allocate funds to maximise quality of life for people with dementia and their families, now and for the future. The second day looked at strategies for achieving this. Li Yu from Taiwan and Glenn Rees from Australia explained how their associations have successfully engaged politicians. One key learning point was that politicians have limited time so you must boil your message down to its essence.

Finally, the associations present were asked to identify objectives that ADI could evaluate in future.

The event demonstrated the spirit

of co-operation and collaboration that exists in the Asia Pacific region. Participants found it useful to learn from their neighbours and the training prepared them to tackle the challenges they face. One participant explained, 'I feel better equipped to move forward. It is great to know that we are not alone; that we will be supported.'

ADI is planning two Alzheimer University programmes for next year. An advocacy training event will be held in January for ADI members in Copenhagen, Denmark, and training for emerging Alzheimer associations will take place in London, UK, in the spring.



Alzheimer's Disease International

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Send us your comments

If you have any comments about or items for the newsletter please contact the Secretariat. Articles for the next issue of Global Perspective to arrive by **31 October 2005**.

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Editorial



Henry Brodaty
Chairman, ADI

In 2002 I was privileged to become chairman of Alzheimer's Disease International. Since then there has been substantial progress on two parallel planes.

On the one plane, there are rapid technological advances and exciting promises of earlier detection and better treatments. For example, new scanning techniques make it possible to see the brain changes associated with Alzheimer's disease in living people. With advances in drugs that act against these changes in the brain it may become possible to reverse, halt or even prevent the development of Alzheimer's disease.

On the parallel plane, ADI and Alzheimer associations are shedding light where too often darkness prevails – ignorance, stigma, lack of diagnosis, little or no support for families and scarce services for people with dementia. ADI has championed awareness, encouraged the formation of new Alzheimer associations and supported existing member associations.

As ADI has grown, we have been mindful of the need to reorganise ourselves to be more inclusive and more efficient. ADI now has a person with dementia on the board. We have adopted more streamlined governance and we have targeted new Alzheimer University training programmes to better meet the needs of our members.

I am optimistic that ADI and Alzheimer associations worldwide will continue improve the quality of life for people with dementia and their families.

Announcements and conferences

2005

15–20 August
5th Brazilian Alzheimer's Congress
Latin American ADI and Alzheimer Iberoamerica Regional Meeting
Belo Horizonte, Brazil
Tel: +55 11 5574 7446
Email: abraz@abraz.org.br
Web: aib.alzheimer-online.org/content/view/38

31 August – 2 September
International Mental Health 2nd Annual Conference
Mental Health and the Millennium Development Goals
Institute of Psychiatry Second Annual Conference
London, UK
Email: imh@iop.kcl.ac.uk
Web: www.iop.kcl.ac.uk/international/conference

16–18 September
Alzheimer's Society (UK) Annual Conference and AGM
Warwick University, UK
Tel: +44 20 7306 0606
Email: enquiries@alzheimers.org.uk

20–24 September
Aging with Dignity 12th International Psychogeriatric Association Congress
Stockholm City Conference Center, Sweden
Email: ipa@ipa-online.org
Web: www.ipa-online.org/congress

1–2 October
Regional Symposium on Alzheimer's Disease and Related Disorders in the Middle East
Istanbul, Turkey
Tel: +90 212 533 8575
Fax: +90 212 533 4393
Email: muratemre@superonline.com
Web: www.worldeventsforum.com/alz.htm

7–8 October
First Uruguayan Congress on Dementias
Montevideo City Hall Convention Centre
Montevideo, Uruguay
Tel/Fax: +598 2 901 31 76
Email: demencias2005@atenea.com.uy
Web: www.atenea.com.uy

21 October
Wellness for Persons with Dementia Boston Alzheimer's Symposium
Marlborough, MA, USA
Tel: +1 617 469 5800
Email: alzsymp@rogerson.org

20–23 October
4th International Congress on Vascular Dementia
Porto, Portugal
Tel: +41 22 908 0488
Fax: +41 22 732 2850
Email: vascular@kenes.com
Web: www.kenes.com/vascular

5–13 November
18th World Congress of Neurology
Sydney, Australia
Tel: +61 2 9241 1478
Fax: +61 2 9251 3552
Email: info@wcn2005.com
Web: www.wcn2005.com

28 Sept – 1 Oct
21st International conference of ADI
Bridge at the Crossroads
Istanbul, Turkey
Tel: +90 216 330 9020
Fax: +90 216 330 9005
Email: congress@topkon.com
Web: www.adi2005.org

12–14 November
XI National Conference of ARDSI
Dementia and Care – An Indian Perspective
Trivandrum, India
Tel: +91 471 2524523
Fax: +91 471 2524584
Email: demcon2005@gmail.com
Web: www.sctimst.ac.in/demcon2005

17–20 November
2nd International Congress on Brain and Behaviour
Thessaloniki, Greece
Email: kfount@med.auth.gr
Web: www.psychiatry.gr

15–16 December
Iranian Alzheimer Association (IAA) 1st International Conference
Tehran, Iran
Tel/Fax: +98 21 4651122
Email: info@alzheimer.ir
Web: www.alzheimer.ir

Visit www.alz.co.uk/events for more conference announcements



Carer's story

By Chantana Boonsrisuwan, Bangkok, Thailand

Little things can make a difference

Mother first showed signs of dementia nine years ago. She would talk to herself about things in the past and get upset. She would see herself in the mirror and call out or talk to the image. Sometimes she would even try to reach out to it, not knowing it was herself.

Places confused her and she became afraid to be alone; she had to be near us at all times, even when we were working. If she was napping, we would be called to come and sleep with her. Once we lost her in a hospital for two hours. We had told her to sit and wait but she could not remember.

The first four years of looking after mother were very stressful because we were constantly answering her questions and explaining reality to her. This took a long time. Sometimes she would be appeased, but other times we would be at loggerheads because she would not accept our reasoning.

In recent years, because the family has made changes, mother has been able to live her life more happily. We have looked for ways to resolve our



Chantana (left) with her mother (centre) and her sister

conflicts and reduce the confusion in her world.

We note down her frequently asked questions and write a standard answer for her to read every time she asks. We find that after two or three times, she doesn't ask any more. We also try to stimulate her memory by reminding her of facts about herself and the family. We use photos to remind her of the names and ages of family members and friends.

Practical adjustments have been made to the home to avoid dangerous situations. For example, the bathroom door lock has been taped up so she does not lock herself in. Also, whenever we leave the house, we leave mother a note to say where we are going.

My family work hard to reduce mother's anxiety and improve her mood. When people are talking, we

make outreaches to engage her in the conversation. We take her to see the family that she really loves or ask them to call her.

Little things make a difference too. We take mother to all the family occasions, we ensure she exercises and encourage her to say her prayers. About two years ago I joined a support group. I felt like I had been relieved of a heavy burden – like coming from the darkness into a bright place.

One meeting that really made a difference to me was when a psychiatrist spoke about situations of conflict. Following his advice, I go with my mother's actions, thoughts or words, whether they are rooted in reality or not. This helps to calm her down and afterwards I can explain. With difficult questions, we will try to give her an answer that she wants to hear or does not aggravate her. This stops us from going round and round in circles.

To this day, we are living together much more happily. We have better learnt how to deal with mother's thoughts and needs and she is much happier. We are proud that our home is now full of warmth and love.

World Alzheimer's Day
21 SEPTEMBER 2005



Help us raise awareness about dementia and tackle stigma

Alzheimer associations across the globe are busy planning how they will mark World Alzheimer's Day on 21 September.

Our World Alzheimer's Day bulletin – which includes testimonies from across the world and different sections of society – is now online.

This year, ADI staff will take part in a Memory Walk and write to all the world's health ministers. We want to know what you have planned.

To find out how you can make a difference and what events are planned worldwide, to read the bulletin and to tell us your plans visit: www.alz.co.uk/WAD

Members' forum

ADI members: do you have any news you would like to share with the global dementia community? Please contact us.

Australian government recognises dementia as a national health priority



Glenn Rees, National Executive Director of Alzheimer's Australia, with Australian Minister for Ageing, The Hon Julie Bishop MP

The Australian government have made dementia a National Health Priority, as a result of five years of consistent lobbying from Alzheimer's Australia. The government have allocated a budget of AU\$320 million over five years for better prevention, treatment and care. Glenn Rees, National Executive Director of Alzheimer's Australia, commented, 'the budget will give people with dementia, and their family carers, confidence in the commitment of the Australian government to address the dementia epidemic now and in the future.'

The Australian Dementia Manifesto



Bulgaria and Romania share challenges and solutions

Vladimir Penev and Zhivka Tisheva from Compassion Alzheimer Bulgaria recently visited the Romanian Alzheimer Society's (RAS) Memory Clinic to see the challenges of diagnosis management, care and project co-ordination firsthand. Eugen Stefanut and Catalina Tudose of RAS also shared details of their awareness campaign, 'Do Not Forget Those Who Forget', and their support group programmes. Finding common challenges and sharing solutions was useful for both associations.

Vladimir enthused, 'I got some very useful advice and great ideas for our future work.' Catalina explained that it was good to evaluate their programmes; 'Small steps, perseverance and patience are very important in changing mentalities and increasing awareness of dementia issues in our region.' Both associations look forward to strengthening their partnership and working together as neighbours.

Mouties and Ministers at Canadian conference

'Broadening Our Horizons', the Alzheimer Society of Canada's 27th annual conference, was held in Regina, Saskatchewan in April. Over 350 delegates heard presentations by Saskatchewan's Minister of Health, John Nilson, and people with dementia, Lynn Jackson, President of Dementia Advocacy and Support Network International, and Marilyn Truscott. The event also attracted international delegates. As Debbie Krulicki, Media Relations and Communications Manager, explained, 'We were especially pleased to host two delegates from Trinidad. We have been partnered with the Alzheimer's Association of Trinidad and Tobago for the past few years. It is always great to see them face to face.'

A piper and two Mouties lead delegates at the opening ceremony of the Canadian conference





(Left to right) Aida Shawwaff, Diane Mansour, Nabil Naja and Mounir Khani at a press conference during the 1st Arab conference

Middle East: Impetus for Change

The Arab conference held in Beirut this March was the first of its kind. Hosted by Alzheimer's Association Lebanon, it marked the beginning of a new era for the Middle East. Lebanese and international delegates gathered to discuss training, research and policy development. The event achieved widespread media coverage. Conference organiser Diane Mansour commented, 'The presentations were thought provoking and after each the room was buzzing with questions.' A consensus statement of eight recommendations was generated by the conference and an umbrella group was formed to encourage new associations in the region.

Strategic direction in Puerto Rico

After participating in the Alzheimer University in 2004, the Alzheimer's and Related Disorders Association of Puerto Rico decided it was time to update their strategic business plan. Key objectives include: raising public awareness about the need for early detection and intervention, providing appropriate care services, fundraising for new headquarters and developing fundraising initiatives.

So far they have set up a support group for people with early stage dementia, held an educational event and set up groups to develop fundraising activities and to raise public recognition through World Alzheimer's Day. Plans are currently underway for a Gala in August and a Memory Walk in September. Lilliam Valcárcel, Treasurer, commented, 'The enthusiasm to improve the quality of life for people with dementia and their relatives that the pioneers had 12 years ago is still with us today.'

Encouraging earlier diagnosis in Portugal

APFADA is conducting a research project following people with early stage dementia. In the three-year project, 30 people with dementia and their families will regularly meet specialists, including occupational therapists and neurologists, to analyse their physical and mental changes. It aims to make early diagnosis easier and to overcome common misconceptions about the disease. Pedro Neves expressed his optimism, 'in my country, there is still a long way to go with raising awareness and building knowledge in the professional community. We hope that the outcomes of this research [a Manual of Good Practice] will lead to earlier diagnosis of dementia and better quality of life for people living with the disease.'

Great leaps forward in Malta

Less than a year after its launch, the Malta Dementia Society has a lot to be proud of. The committee, a combination of both healthcare professionals and carers, set out the focus of the association's work: providing carers with information and education. So far they have run educational sessions about challenging behaviour and daily routines for carers and produced an information sheet and a website. The Society is looking forward to the Memory Walk, media campaigns and information displays that they plan for this year's World Alzheimer's Day. In the near future, they hope to train professionals about diagnosis and caring for people with dementia.

Visit www.maltadementiasociety.org.mt for more information.

Charles Scerri, Secretary, and Stephen Abela, Chairperson, of the Malta Dementia Society



■ Living with dementia

ADA gives new horizons to people with dementia

Following Myrna Blake's ground-breaking public speech about her dementia diagnosis in 2004, the Alzheimer's Disease Association (ADA) in Singapore are making strides in developing services for people with all stages of dementia.

The New Horizon Centre in Toa Payoh is one of three centres that provide activities and stimulation for people with dementia. A recent upgrade at the Toa Payoh centre has enabled ADA to run services for people with early and moderate dementia, as part of their Early Dementia Programme. Activities include an arts hour, aerobics and reflexology. One lady described her experiences with enthusiasm, 'I look forward to coming because no two days are the same. I spend time with my friends enjoying the garden or talking about old times in the reminiscence corner.' Theresa Lee, Executive Director, said, 'It is important that everyone has an interesting day. We want people to use and develop many skills.'



The New Horizon choir entertain guests at ADA's fundraising dinner in May

In addition, a 'Living with memory loss' pilot support group was established. People with early stage dementia who attended discussed topics such as 'experiencing dementia' and 'communication issues' in a safe

environment. The pilot group was a success and ADA will continue to expand their work as part of their Early Dementia programme. They hope to share experiences with others who are interested in starting similar services.

First hand experiences of dementia give insight

A new section on the DIPEX website was launched in March for carers of people with dementia. The DIPEX website gives personal accounts of health and illness. In written, audio and video dialogue, visitors to the site learn what it is really like to live with a medical condition. Carers can now access the personal experiences of others and use them to make better-informed choices about their lives.

The DIPEX website is a creation of two UK doctors, Ann McPherson and Andrew Herxheimer. Both had their own health problems and their

experiences showed them how much can be learned from other patients. The DIPEX site enables everyone to do this.

It was important to include a range of experiences. As Dr McPherson explains, 'We wanted not just people who managed well but those who had difficulties too.' For the dementia section, thirty-one carers of people with dementia aged from 40 to over 80 were interviewed. They are spouses, partners, sons and daughters who care for people at different stages of dementia.

Along with the interviews, you will find answers to questions frequently asked by carers, information about the different types of dementia, the legal issues faced by carers and advances in treatment.

The site is always evolving. New people visit and share their experiences, adding to the richness of the information. It is a resource to take from and contribute to. The creators hope that people with dementia and their carers will find it valuable and will share their thoughts through the forum or by emailing them.

You can visit the site at: www.dipex.org/dementia

■ Research update

Prevention conference

The results of a number of important pieces of research were presented at the Alzheimer's Association International Conference on Prevention of Dementia, held in Washington, DC from June 18–21.

New research on lifestyle habits was presented – social activity, higher levels of education, exercise and drinking fruit and vegetable juices may all help to reduce the risk of dementia in later life.

Advances in imaging technologies and new biomarkers were reported which may allow earlier diagnosis of Alzheimer's disease, even before symptoms begin to become apparent.

A number of new approaches to treatment were presented, including a new version of an anti-inflammatory drug, the passive administration of antibodies to beta amyloid and an herbal extract based on traditional Chinese medicine.

Work was also presented on screening for dementia in primary care. A large proportion of people are only diagnosed once their dementia is advanced, and one reason given for this is the lengthy nature of interviews used in the current screening tools. Existing alternative tools were found to be just as accurate, but are quicker and easier to perform.

Finally, the first estimate of the worldwide direct costs of Alzheimer's disease and dementia care was presented. The estimated figure for 2003 was \$156 billion. Although there are several sources of uncertainty in the calculation, it is clearly a huge sum, and with the numbers of people with dementia worldwide set to increase rapidly, underlines the need for action to meet the challenge of dementia.

<http://www.alz.org/preventionconference/pc2005/>

Dementia and obesity

Researchers in California published an important study in the BMJ Online in April, reporting a significant link between dementia and obesity. They found that people who were obese in middle age had a more than 70% increased risk of dementia in old age. The increase in risk for women was found to be higher than that for men.

The results were based on a study of more than 10,000 people in North California who were assessed initially in the late 1960s and early 1970s.

The findings are consistent with other studies that have shown that high blood pressure and high cholesterol, which are associated with obesity, are also risk factors for dementia.

Dr Steven DeKosky, chairman of ADI's medical and scientific panel, commented, 'We are paying increased attention to ways to prevent dementia from occurring, or delay its symptom onset. These data are important not only because they provide insights into the mechanisms that cause dementia, but also provide rational, evidence-based reasons to control hypertension in midlife, pursue healthy diets, and other similar activities. While not proven to prevent or delay dementia, the evidence is increasing that they may well do so, and they certainly have reason to be recommended based on the other health-promoting outcomes they produce.'

<http://bmj.bmjournals.com/cgi/content/abstract/330/7504/1360>

■ News



ADI's Medical and Scientific Advisory Panel Chair wins award

In April, Dr Steven T DeKosky, Chairman of ADI's Medical and Scientific Panel (MSAP), was awarded the prestigious Ronald and Nancy Reagan Research Institute Award in Washington, DC. He commented, 'This is real honour. I am committed to my research and to finding a cure to this devastating disease. The people with dementia and carers I meet spur me on in this mission.' Steven will complete his term as MSAP chair in October, although he will remain a member of MSAP. We would like to congratulate him on his achievement and thank him for all his hard work.

How to include migrant care workers

The Alzheimer's Society UK Quality Care team have identified that migrant care workers in the UK are often excluded from dementia care support networks. This trend needs to be reversed. They plan to research ways to be more inclusive – for example, by developing materials that will better support them. The proposal is still being developed but your knowledge can help now! Daren Felgate of the Quality Care team would like to hear if you are facing a similar issue. Email him at: qualitycare@alzheimers.org.uk.

Spirituality and dementia

The 6th Stroud Symposia workshop will take place at the ADI Istanbul conference and is themed around Spirituality and Dementia. The brainchild of Professor Barry Gurland, previous Stroud workshops have explored a number of areas and their impact on quality of life for people with dementia. Previous themes include choice, the carer/person with dementia relationship and what improves/reduces quality of life. The findings so far will be reviewed in Istanbul but you can access a summary of all the data at www.stroudsymposia.org. This year's theme is a growing area of research and interest. Like its forerunners, this workshop will be spontaneous in spirit and interactive in nature. Newcomers and those who have participated in earlier workshops are very welcome to attend.

■ Hot Topic

Should Alzheimer associations lobby for government funding of anti-dementia drugs?

Following the draft recommendation by NICE (the independent organisation responsible for providing guidance on treatments for people using the National Health Service in England and Wales) that anti-dementia drugs should no longer be used in the treatment of mild to moderate Alzheimer's disease, we asked members for their opinions.



Hussain Jafri: Secretary General, Alzheimer's Pakistan

YES For NICE to acknowledge

that the drugs have benefits to patients but recommend that they not be subsidised is the worst violation of human rights I can ever think of. It is unfair to abandon those senior citizens, who have contributed actively to their community and country in the prime of their life. We must raise our voices for those who are not in a position either to understand or to protect their own rights.



Neil Hunt: Chief Executive, Alzheimer's Society UK

YES We are battling to stop people with

dementia being made to pay for drugs which have a real impact on their quality of life.

Many years of progress in the fight against dementia in the UK will be lost if we do not overturn the draft guidance issued by NICE.

Campaigning is not an optional extra for us, it is essential for delivering hope, support and choice to people with dementia, their families and carers. It needs to be central to our role. We must lobby governments to ensure that the health and social care systems that exist across the world play their full part in helping us to overcome dementia.



Wendy Fleming: Chairman, Alzheimer's New Zealand

YES Of course! In New Zealand drug treatments can cost

up to \$300 a month – too much for many people that really need them.

Since 2001, we have been lobbying our government to subsidise these medications. We believe that people with dementia are entitled to quality health care and affordable access to treatment.

Drug treatments can slow down the progression of dementia. They give people with dementia, their families and carers quality time together. All those people who could benefit from drug treatment should have the opportunity to receive it. If access to medication is dependent on ability to pay, the result is health inequalities between the rich and poor.



Jim Jackson: Chief Executive, Alzheimer Scotland

YES Most certainly! Lobbying for

drugs is a good example of where Alzheimer associations can be more influential than individuals or small groups of people with dementia and their carers. By making a well-argued case, supported by as broad a membership as possible, Alzheimer associations can demonstrate their effectiveness and increase their national and local recognition.



Marc Wortmann: Chief Executive, Alzheimer Nederland

YES We were happy when

a second anti-dementia drug was approved by the European drug authority and made available to the Dutch. But the government decided that the new drug had little therapeutic impact and withdrew its funding. We protested, but we got nowhere.

A new approach was needed. We launched a fundraising campaign called the special Dementia Emergency Fund. Targeting 110,000 donors we raised €160,000 to subsidise a year's worth of drug treatment for 150 people with dementia. The campaign got the attention of the national media and several members of Parliament were recruited to the cause. Two years on, the government has agreed to fund drugs but only for people with severe forms of dementia. We still have work to do.



Daisy Acosta: Chairman, Asociacion Dominicana de Alzheimer

YES In this country dementia

drugs are not subsidised and they are very expensive. I ask, why can't every person with dementia and every family have these benefits? Do we have the right to take away from them what we have to offer? The answer is no.