

## Alzheimer's Disease International -thank you for 20 years of caring

Brian Moss, Honorary Vice-president, Alzheimer's Disease International

Following a visit to the US in 1982 (as part of a world-wide study tour to learn how other countries provided care for people with dementia) two events stay clearly in my mind.

The first was an inspirational meeting with Jerome Stone in Chicago where he introduced me to the Alzheimer's Association (USA).

The second was a meeting with a leading researcher at the National Institute of Health in Washington DC. During our discussion I asked 'How long before a cure for Alzheimer's disease is discovered?' His reply 'It will probably be at least a decade before we find the cause, and then we are not talking about cure, only prevention!' When I met the same researcher a decade later, I reminded him of his prediction and enquired as to where we may be heading. His answer: 'Although progress has been made it could still be another decade!'

It is abundantly clear that the work of ADI is needed for decades to come. As we proceed into the 21st century there is as yet no diminution but rather an increase in the number of people with dementia around the world.

As ADI's first chairman, I think we can be justifiably proud of ADI's achievement of encouraging and nurturing national associations in numerous countries around the world over the past 20 years. This has led to a far better understanding of dementia and the ramifications for



(Right to left) Past, present and future chairmen of ADI: Brian Moss, Nori Graham, Henry Brodaty and Orien Reid

those with dementia and their carers. And this in turn has led to many innovative support services. National governments in many countries have come to realise the implications of the need for adequate planning, and financial support for carer organisations. Research has been pursued with vigour, and, whilst the elusive cause and cure are yet to be achieved, there is hope.

Thank you ADI for leading the way, for the gritty determination to improve the life and circumstances for people with dementia and their carers. Thank you for providing me with an opportunity to play a small part and for the many friendships developed over the years.

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### ADI conference brings hope to Kyoto

Over 4000 delegates participated in ADI's largest conference to date. The meeting generated 73 million media impressions throughout Japan as Japanese people with dementia spoke publicly for the first time about their illness. Full conference report on pages 10-11





## 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 **15 February 2005**.

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## Announcements and conferences

### 2005

3-4 March  
Alzheimer's Association  
Lebanon  
**The Arab Conference on Alzheimer's Disease**  
Beirut, Lebanon  
Fax: +961 3 245 606  
Web: [www.alzlebanon.org/Conference/conference.asp](http://www.alzlebanon.org/Conference/conference.asp)

9-13 March  
**7th International Conference on Alzheimer's Disease and Parkinson's Disease**  
Sorrento, Italy  
Tel: +41 22 9080488  
Fax: +41 22 7322850  
Email: [conventions@kenes.com](mailto:conventions@kenes.com)  
Web: [www.kenes.com/adpd](http://www.kenes.com/adpd)

11-13 May  
**Alzheimer's Australia National Conference**  
*Living with Dementia – Positive Solutions*  
Sydney, Australia  
Email: [krennie@alznsw.asn.au](mailto:krennie@alznsw.asn.au)  
Web: [www.alzheimers.org.au](http://www.alzheimers.org.au)

8-12 June  
**2nd Congress of the International Society for Vascular Behavioural and Cognitive Disorders**  
Florence, Italy  
Tel: +39 055 456531  
Fax: +39 055 4565440  
Email: [info@regiacongressi.it](mailto:info@regiacongressi.it)

9-12 June  
**15th Alzheimer Europe Conference**  
*Dementia Matters*  
Killarney, Ireland  
Tel: +353 1 622 0125  
Fax: +353 1 662 0126  
Email: [info@conferenceorganisers.ie](mailto:info@conferenceorganisers.ie)  
Web: [www.alzheimer-conference.org](http://www.alzheimer-conference.org)

18-21 June  
**Alzheimer's Association International Conference on Prevention of Dementia**  
*Early diagnosis and intervention*  
Washington D.C., US  
Tel: +1 312 335 5790  
Email: [info@alz.org](mailto:info@alz.org)  
Web: [www.alz.org](http://www.alz.org)

27-29 June  
**International Association of Homes & Services for the Ageing**  
*Creative Solutions for an Ageing Society: Sharing the Wisdom*  
Trondheim, Norway  
Email: [iahsa@aahsa.org](mailto:iahsa@aahsa.org)  
Web: [www.aahsa.org/iahsa/iahsaonline/Proposal](http://www.aahsa.org/iahsa/iahsaonline/Proposal)

14-19 August  
**12th IPA Congress**  
Stockholm, Sweden  
Email: [ipa@ipa-online.org](mailto:ipa@ipa-online.org)  
Web: [www.ipa-online.org](http://www.ipa-online.org)

28 September – 1 October  
**21st International Conference of Alzheimer's Disease International**  
*Bridge at the Crossroads*  
Istanbul, Turkey  
Tel: +90 216 467 06 47  
Fax: +90 216 467 06 51  
Email: [congress@topkon.com](mailto:congress@topkon.com)  
Web: [www.adi2005.org](http://www.adi2005.org)  
Abstracts deadline: 1 March

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](mailto:muratemre@superonline.com)  
Web: [www.worldeventsforum.com/alz.htm](http://www.worldeventsforum.com/alz.htm)

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](mailto:vascular@kenes.com)  
Web: [www.kenes.com/vascular](http://www.kenes.com/vascular)

Visit [www.alz.co.uk/events](http://www.alz.co.uk/events) for more conference announcements

## Editorial

I had a visit yesterday from Karen Borochowitz, Chairman of the Western Cape Region of Alzheimer's South Africa and a graduate of the Alzheimer University. It struck me clearly during our discussion that there is no doubt that the fundamental reasons we were founded in 1984 are still valid today. We are here to foster and encourage the development of Alzheimer associations. Karen described with passion the successful events and media coverage for World Alzheimer's Day and the challenges of a growing association. I was impressed that 370 people regularly attend support groups each month in 17 locations across the region. We talked about how hard it is to persuade policy makers to take notice of dementia, especially in a region where life expectancy is low and AIDS is the major health concern.

It was invaluable for me to hear first hand how being part of ADI is of direct benefit to others. Karen's energy and enthusiasm for building Alzheimer's South Africa inspired me. She brought home to me that the challenges Alzheimer's South Africa face are the same ones ADI face. We too are a young organisation, with a few staff, some dedicated volunteers and not much money but trying to make a difference.

And we are making a difference. There are now over 70 Alzheimer associations worldwide – 20 years ago there were four. Our goal for the next 20 years must be to have an Alzheimer association in every country of the world.



**Elizabeth Rimmer**  
Executive Director

### Correction

There was a error on page 5 of the July 2004 issue of *Global Perspective*. Roberto Garcia was the former chairman of AMAES and not, as stated, of Federacio Mexicana de Alzheimer. Apologies for any confusion caused.



## Carer's story

# My grandmother's strong legs

By Jonas Lautrop, Denmark

**M**y grandmother, Kirsten Ewaldsen, was a sociable and creative person who made her living as a draughtsman and a painter. She was also a journalist and a creator of a famous Danish theatre group.

She died from Alzheimer's disease in 1995 at the age of 67. Although she probably had the disease for 10 years, she was only diagnosed in 1993. So for many years we didn't know what was wrong with her – was she depressed, crazy, or what? But as soon as we learnt about her illness, it became easier to cope with Kirsten's disease. We realised then that she was in a helpless situation and all we could do was give her tender, loving care.

**My mother thought that if Kirsten understood the depths of the diagnosis, it would break her heart**

My mother was the first to be told the diagnosis and decided there was no reason in telling Kirsten the whole truth. She thought that if Kirsten understood the depths of the diagnosis, it would break her heart. Instead, she told her 'Kirsten, your memory doesn't work that well anymore. But don't worry, you still have your strong legs.' Kirsten laughed, because she *did* have strong legs.

It was Kirsten's strong legs that made it possible for her to move into a nursing home shortly after her diagnosis. Until then she had lived in her own apartment. The nursing home had a vacant room on the third floor, which could only be reached by climbing some steep stairs – something Kirsten could manage.

Even though Kirsten was extremely mentally impaired, my mother insisted that she be allowed to go for walks whenever she wanted. The staff at the nursing home didn't like that idea. My mother explained that Kirsten had always been devoted to her personal freedom and taking this away would make her feel like a prisoner.

**I'm convinced that because Kirsten kept her personal freedom, she felt a kind of meaning in life**

Hence, Kirsten spent her last years on this earth as a free bird. She could walk in the forest and sense the mighty trees and the green leaves, or down to the sea and watch the waves. I'm convinced that because Kirsten kept her personal freedom, she felt a kind of meaning in life – even though she couldn't express it in words. Every time she returned from one of her walks her eyes would be sparkling like a teenager in love.

**We would create a fantasy that she could understand and give her a role to play**

The nursing home was very close to our house and Kirsten would often drop by unannounced – sometimes at inopportune moments. We couldn't explain this to her so, we would create a fantasy that she could understand and give her a role to play.

It often went like this. Imagine it is a Saturday. My mother, sister and I are gardening. Suddenly Kirsten is there. But instead of telling her 'Oh, Kirsten we don't have time to take care of you right now' we would say,

'Oh, how lucky you came by Kirsten. You are much needed because we are pretending that we are native Indians doing the gardening, but we need a native Indian chief to keep an eye on us. Can you be the chief?' In reply she would always smile and play whatever role we had assigned her. Then she would sit in a chair with a blanket around her, and every once in a while we would ask her 'Well, how do you think your native Indians are doing? Good?' 'Yes', she would nod. So we made her feel a useful part of the community.

**We turned a potential conflict into a good experience for everybody**

But we would always reach the moment when Kirsten had to go home. And sometimes she didn't want to go home. She couldn't express that feeling in words but I could see it in her body language. When that happened we would change the role she was to play and might say 'Kirsten, you are a princess, and you have to go home to your castle.' 'Oh, I'm a princess – not bad' she seemed to think.

In that way we turned a potential conflict into a good experience for everybody. But most important of all, by role-playing we kept alive what was left of the Kirsten who once was the artistic free spirit.

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*Kirsten Ewaldsen kept a diary up until two years before her death. Jonas Lautrop published Kirsten's Diary – a life with Alzheimer's Disease based on her dairies. The book is available in Denmark and Norway. For further information contact: [jonaslautrop@hotmail.com](mailto:jonaslautrop@hotmail.com)*

# Members' forum

## ADI membership grows to 69

Welcome and congratulations to Alzheimer Association of Iran, Alzheimer's Association of Lebanon and Associação Portuguesa de Familiares e Amigos de Doentes de Alzheimer, who were all recently accepted as members of ADI.

### ● Korea

#### Outstanding citizen award



Mrs Sung-Hee Lee

Congratulations to Mrs Sung-Hee Lee who was awarded the 'myung nyung jung' – the highest ranking medal awarded to a citizen. The medal, presented by the president of South Korea in Seoul, was awarded on the Day of the Elderly (2nd October) for outstanding civil service in senior welfare. Sung Hee Lee was honored for establishing the Alzheimer's Association Korea in 1991, spreading the recognition of dementia as a disease, and designing and operating the first senior welfare center and nursing home for people with dementia in Korea.

### ● Australia

#### Prime Minister makes commitment to dementia

In the recent Australian Federal Election, the Coalition Government led by Prime Minister Howard

committed itself to making dementia a National Health Priority. At the launch of the Coalition's election policy, the Prime Minister made a four year commitment to support the following:

- AU\$52 million to develop and monitor strategies to improve health outcomes for people with dementia
- AU\$128 million to provide 2,000 high care packages in the home specifically targeted to people with dementia
- AU\$20 million to expand the Carer Education and Workforce Training Project to provide dementia-specific training.

With the re-election of the Coalition Government, Alzheimer's Australia is looking forward to working with the government to deliver on these commitments.

Alzheimer's Australia has advocated that dementia should become a National Health Priority because it will be a major challenge for the public health system in terms of numbers of people, health costs and disability burden. Alzheimer's Australia also expects the government's commitment will promote awareness, improve quality of dementia care, assist in promoting the potential for risk reduction and lead to a greater investment in dementia research.

The basis for this advocacy campaign was laid out in the report commissioned by Alzheimer's Australia from Access Economics *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia*. This was followed by the Dementia Manifesto which set



out the commitments Alzheimer's Australia sought from the political parties and a report by researchers led by Professor Zaven Khachaturian *Dementia Research: A Vision for Australia*. All these documents are available at [www.alzheimers.org.au](http://www.alzheimers.org.au)

### ● Scotland

#### Adults with Incapacity Act

Alzheimer Scotland has welcomed news from the Scottish Executive that it is monitoring the implementation of the Adults with Incapacity Act 2000 (Scotland).

The Act was a great step forward for people with dementia and other forms of mental incapacity and is one of the most advanced pieces of legislation on incapacity in the world. It provides a protective legal framework for people who have lost the capacity to make decisions and mechanisms for making decisions about personal finances, medical treatment and care which take into account the views of people with dementia.

Jim Jackson, Alzheimer Scotland's executive director, also welcomed the announcements of free legal aid for welfare guardianship proceedings, which Alzheimer Scotland had been campaigning for, and the secondment of Jan Killeen, Alzheimer Scotland's public policy director, to the Scottish Executive as

National Practice Coordinator. Jan will take a leading part in ensuring that the Act's objectives are fully realised.

### ● Singapore and Armenia Innovative practices

The Alzheimer's Disease Association (ADA) in Singapore has been working with a group of prisoners on a project to develop computer software with memory games and activities for people with dementia. ADA's initiative, one of the 50 sponsored by City Bank's Youthful Causes Project, won the most inspiring, challenging and bravery award. One boy said he felt that putting something back into society had given him a second chance. ADA has used this project to raise funds and dementia awareness amongst a group of disadvantaged people.

Meanwhile the emerging Alzheimer Association of Armenia's efforts to conduct a prevalence study have run into several difficulties – the biggest of which is the lack of dementia awareness amongst Armenia's three million inhabitants. Not to be defeated, the Association is thinking of training postmen to identify people with dementia. Postmen are seen as ideal for this role as they have good community knowledge and constantly visit people's homes.

### ● UK

#### Partners in Care

ADI is delighted that the World Alzheimer's Day 2003 factsheet *In Perfect Partnership* has been adapted for a leaflet on dementia produced by the Royal College of Psychiatrists and the Princess Royal Trust for Carers. The leaflet identifies important questions both carers and professionals should ask each other and is one of several developed for the 'Partners in Care: working together to make a real difference' campaign.

The College's campaign aims to help carers of people with mental health problems and learning difficulties by promoting effective communication and partnerships between mental health professionals and carers.

Visit [www.partnersincare.co.uk](http://www.partnersincare.co.uk) for more information.

### ● UK

#### After Dementia Millennium Awards

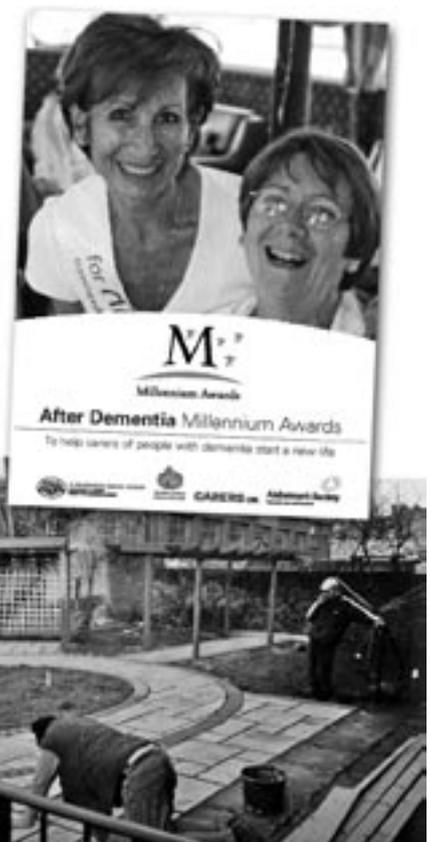
The After Dementia Millennium Awards scheme was set up to enable carers of a person with dementia to rebuild their lives, confidence and social networks. The scheme was funded by the Millennium Commission and run by the Alzheimer's Society, Alzheimer Scotland and Carers UK.

The scheme ran from September 2001 to June 2004 and gave 261

Awards to carers aged between 30 and 90. It funded 131 projects at a total cost of £820,000 including the creation of a garden in London and the production of the video *Life with Two Hats*.

The sensory and memory garden created at Grange Day Centre in London brings nature to people with dementia in a safe and secure environment. The garden provides smells, sensations, light, water, tranquility, activity, work and exercise. In this culturally diverse area of London, the garden also helps break down the barriers to communication that language can impose.

The short video *Life with Two Hats* by Viviana Fain-Binda gives an insight into caring for someone with dementia. At the video launch, Viviana, who cared for her mother, said 'When you look after somebody with dementia, you wear two hats: the "Florence Nightingale Cap of Compassion" looking after the physical and mental needs and "The Warrior Helmet" battling your way to find out what services and benefits are available.'



**Below: The After Dementia Millennium Award sensory garden at the Grange Day Centre in London**  
**Right: The booklet of projects supported by the scheme**



**No time to lose as number of people with dementia set to double**

## World Alzheimer's Day

**From Australia to Alaska, a record 59 countries participated in World Alzheimer's Day with the support of ADI. Alzheimer associations around the world were united by ADI's campaign 'No time to lose' on Tuesday 21 September as they raised awareness of dementia and the work of their associations.**

The 'No time to lose' campaign came after findings from the recent pan-European *Facing Dementia Survey* in which 87% of carers and 71% of physicians felt their governments do not invest enough in treating dementia.

In response to this, ADI wrote to health ministers in 192 countries alerting them to the enormous economic consequences of an ageing population and calling on them to provide better support services for people with dementia. Elizabeth Rimmer, ADI's executive director, told journalists 'Dementia is an expensive disease. In the UK's elderly, the cost of dementia is more than that of heart disease and cancer and stroke combined yet

research spending is only 10% of that on heart disease and 3% of that on cancer.'

Some ADI members used the opportunity to lobby governments directly (Australia, Brazil, Peru and Scotland). Others invited government ministers to participate in events such as press conferences (Chile, Germany, Israel, Poland, Spain and Zimbabwe), Memory Walks (Guatemala and Venezuela), conferences (Armenia) and tea parties (Western Cape, South Africa). In India, the Minister for Social Justice and Empowerment released the charter of rights for people with dementia and their carers. In Mexico, FEDMA collaborated with the Secretary of Health to develop 160 training courses for doctors in the country's main cities over the next two years. And the Alzheimer Society of Malta invited the Parliamentary Secretary for the Elderly and Community Care to the launch of their association.

Central to this year's campaign was the active participation of people with dementia. ADI hosted an 'international' reception at the House of Commons in London (UK) where people with dementia, carers, ambassadors and high commissioners from ADI's member countries, policy makers, medical professionals and representatives from Alzheimer associations signed ADI's 'No time to lose' charter of principles for the care of people with dementia and their carers.

In Scotland, members of the Scottish Dementia Working Group met with the health minister to



**A record 21 Alzheimer associations took their 'No time to lose' campaign to the streets by organising Memory Walks like this one in Pakistan**

discuss the importance of early diagnosis, respite care and access to medication. In Singapore, Dr Myrna Blake, a prominent figure in the social services field, was the first person to speak publicly about her diagnosis of dementia.

Memory Walks were a prominent feature of this year's World Alzheimer's Day and were held in over 21 countries including Argentina, Australia, Austria, Belgium, Brazil, Cuba, UK,

**Children from two schools in central Falkirk released balloons for Alzheimer Scotland**



### ADI appeals to world's health ministers

**Phoebe Rope, ADI's administrator, posted letters to 192 health ministers around the world, urging them to make dementia a higher healthcare priority**





Guatemala, Hong Kong SAR, India, Israel, Luxembourg, Netherlands, Nigeria, Pakistan, Panama, Philippines, Puerto Rico, Sri Lanka, Trinidad and Tobago and Venezuela.

With so many events organised around the world, media coverage was extensive. Most Alzheimer associations received at least one article in their national press but many received extensive national and local press, radio and TV coverage. In Falkirk, Scotland, the local Alzheimer group received radio coverage throughout the day as their local station read out messages



**Jack Moody and Brenda Colloms sign ADI's *No Time to Lose* Charter of Principles at the World Alzheimer's Day House of Commons reception in London**

the group had collected from ADI members around the world.

And in India, the association's campaign attracted great media interest with the arrival of Stephen Carless and Louisa Elliot in Cochin on 21 September. The UK couple



**World Alzheimer's Day was observed in over 1000 centres throughout India reaching young and old. Here a young magician shows his support for the campaign**

set off from Europe in March and drove their 45-year-old Land Rover through Turkey, Pakistan and India on their epic fundraising Holland to Himalayas expedition. Visit [www.holland2himalayas.co.uk](http://www.holland2himalayas.co.uk) to find out more.

**Traditional opera was just one of the activities organised to raise awareness in Taiwan**



## ■ Living with dementia

# People with dementia go public



Myrna Blake (left) at the conference gala dinner with friends. Myrna was the first person with dementia in Singapore to talk publicly about her diagnosis



Christine Bryden talks to journalists about her diagnosis at ADI's conference in Kyoto

**T**wenty-one people with dementia (16 from Japan, five from overseas) participated in ADI's anniversary conference in Kyoto. Not only was this the largest participation of people with dementia at an ADI conference, it was one in which people with dementia had the greatest impact. Highlights included people from Japan speaking publicly for the first time about their diagnosis (see page 10), an interactive quiet room, a press conference led by a person with dementia and several workshops, including one to further involve people with dementia in the work of Alzheimer associations.

### Japan reaches out to people with dementia

As part of ADI's commitment to integrate people with dementia and Alzheimer associations, ADI organised a training workshop to help this year's conference host, Alzheimer's Association of Japan (AAJ), with this endeavour.

The idea for the training came after AAJ said that one of their goals for the conference was to have wider involvement of people with dementia in all areas of the association's work. The association has already developed a work plan to support people with dementia but wanted to consider further how to actively involve people with dementia in their association.

The training, funded by the Great British Sasakawa Foundation, was led by Rachael Litherland, from the UK Alzheimer's Society's 'Learning to Live with Dementia' project. Representatives from AAJ branches, along with staff from the national office, took part.

The Learning to Live with Dementia project was set up three years ago in the UK to enable people with dementia to learn to live with the disease and achieve the highest possible level of self-determination and active participation in their care.

After the workshop, Rachael was confident that the training had sown a few seeds in people's minds. She

said, 'This has been a really fantastic opportunity. At first, I was concerned the training would be lost in translation. But the workshops were really interactive and people were very engaged, asking some challenging questions.'

'Participants were worried that such a programme might not work in Japan given the culture is quite reserved and people are not used to expressing their emotions. Dementia is a very private experience and the participants were not sure that people with dementia would want to share their experiences. They were surprised to learn that we faced similar issues when we set up our project. I think hearing this filled them with confidence that they would be able to reach people with dementia after all. In fact one participant said to me, "I suppose it's like when we started a support group for carers."'

### Life in the quiet room

As at previous ADI conferences, a quiet room was provided for people with dementia – a large bright sunny room, simply furnished with comfortable seats, refreshments, computer facilities, and an outdoor terrace. The room had a spectacular view of a lake, hills and a beautiful, restful and restorative garden with Japanese styled trees and greenery.

Round the clock interpreters and attendants were available. The room was always welcoming and people from around the world were encouraged to chat to one another. Sometimes sad conversations were translated but mainly they were full of fun and laughter, showing that humour can transcend this disease and different languages.

Christine McGregor, ADI's elected board member responsible for supporting people with dementia said, 'I was privileged to visit the quiet room and I retain vivid pictures of what I saw and experienced there, especially Doreen Cairns (from Scotland) getting a Japanese lady with dementia to smile – the first time in so many months that her supporter promptly phoned the family to tell them of her happy reaction.'

In addition, Peter Ashley (UK), set up a computer network for people with dementia like himself who could not attend the conference.

## ■ Research update

### Antibody therapy

In recent years there has been a lot of interest in using antibodies against the abnormal deposits of beta-amyloid protein in the brain that are one of the main characteristics of Alzheimer's disease. A clinical trial of a vaccine based on antibodies was halted in 2002, after some of the people participating in the trial developed encephalitis.

In a new study, published in August in *Neuron* (43, 321-332), researchers from the University of California treated mice, which had been genetically engineered to develop the plaques and tangles, with beta-amyloid antibodies. Three days after injection the immune system of the mice had cleared the beta-amyloid which causes plaques. Two days later the tangles, made up of a different protein, also disappeared. This supports the 'amyloid cascade hypothesis,' which suggests that plaques disrupt cells' ability to clear faulty proteins, thus allowing tangles to develop.

Dr Steven DeKosky, chairman of ADI's medical and scientific panel, commented 'This model is a technical accomplishment, enabling a better model with which to look at interactions of amyloid and tau protein. Although it has limitations, it may prove to be helpful in proof-of-concept studies of pathological cascades or interventions.'

<http://www.neuron.org/content/article/abstract?uid=PIIS0896627304004246>

### New 'chaperone' approach

Scientists from Howard Hughes Medical Institute and Stanford University have developed a new approach also targeting beta-

amyloid build up. Dr Gestwicki and colleagues have designed a small molecule that can recruit a larger molecule, in order to stop beta-amyloid proteins from clumping together.

Developing drugs to stop interactions between proteins is difficult, partly because the drug molecules are much smaller than the proteins – when they attach themselves to the proteins other proteins can still bind elsewhere. By acting as 'chaperone' – attaching to another protein which was brought along with it – the molecule was effectively able to increase its size 15-fold before binding to the beta-amyloid protein fragment. This greatly reduces the ability of other fragments to gain a foothold, and the molecule proved effective at reducing protein clumping.

This work has only been carried out in the lab, but the researchers said that they hoped animal tests would start in a year.

Dr DeKosky commented, 'This is a novel approach using sophisticated protein chemistry to mimic effects we would like to be able to utilize in AD therapy. We await data from animal models to see if there may be effective translation of this interesting lab finding.' Results of the study appear in the October 29 issue of *Science*.

<http://www.sciencemag.org/cgi/content/abstract/306/5697/865>

### Mentally demanding work

Research by Dr Kathleen Smyth and colleagues at Case Western University in Cleveland USA suggests that people who have higher levels of mental demand in their occupations may be at a



**Are people who have higher levels of mental demand in their occupations at a lower risk of developing Alzheimer's disease?**

lower risk of Alzheimer's disease than those who have jobs which are less mentally demanding in their 30s, 40s and 50s. The results were published in the August issue of *Neurology* (63:498-503).

'While this is an intriguing finding that may explain some of the variability with which Alzheimer's disease strikes people or progresses at different rates, some caution has to be used when looking at the results of the study,' commented Dr DeKosky. 'People with more mentally demanding jobs may have other differences in their lifestyles or medical care. However, the results do fit with an increasing amount of evidence to support the idea that keeping your brain active can reduce your risk of developing Alzheimer's disease.'

<http://www.neurology.org/cgi/content/abstract/63/3/498>

# ADI international conference breaks new ground in Japan

**ADI's 20th annual international conference made headline news throughout Japan as people with dementia from Japan spoke publicly for the first time about their diagnosis – a historic moment for the dementia movement in a culture where people are not accustomed to expressing their private lives in public.**

Among those who spoke out was a 73-year old man, who after announcing he had dementia, described how he noticed something was wrong five years ago. Happily retired and an active member of the community, he realised one day driving his car that he had no idea where he was going. Afraid at first to consult a doctor, he was worried that 'one of these days, I won't be able to recognise my family.'

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

Over 4000 people from 66 countries joined ADI in Kyoto from 15-17th October for ADI's



**Mrs Ituyo Nawate, who has dementia, sang traditional Japanese songs at the gala dinner**

largest conference to date, hosted by Alzheimer's Association Japan (AAJ). The conference also marked ADI's 20th anniversary celebrations; a fitting location given that Japan is home to the world's oldest population where there are currently 1.5 people aged 60 years and over for every child and 1.6 million people with dementia.

The three-day conference focused on care, people with dementia and the family, and dementia and human rights. Keynote presentations explored the global impact



**Mr Ochi spoke about his diagnosis of dementia – the first time a Japanese person had spoken publicly about their diagnosis**

of dementia. Harry Cayton, Department of Health (UK), reviewed the role family organisations and ADI have played in improving the lives of people with dementia and their families and argued that endeavour creates hope and hope further endeavour.

Robert Butler, International Longevity Center (USA), spoke about the need for an official Declaration of the Rights of Older Persons and for society to both acknowledge the human abuses of older people and adopt measures to end them.

Denzil Lush, Court of Protection (UK), took an in-depth look at human rights from the specific viewpoint of people with dementia. He argued that privatisation and globalisation could impede the advancement of human rights as governments, who have formerly assumed responsibility for delivering health and social care programmes, are now increasingly devolving their functions from the national to the local level, or transferring them entirely from the public sector to the private sector.



**Kunio Takami, AAJ President (left), and Yoshio Miyake, AAJ Vice-president (above), worked relentlessly to make the conference the great success it was**

ADI workshops included 'Nothing about us without us! Advocacy by people with dementia' where Christine Bryden (Australia), who has dementia, argued that until people with dementia are engaged locally, nationally and internationally, the Alzheimer's movement will not hear their voice, and policies and programmes cannot be adequately designed to meet their needs. In the 'changing role of Alzheimer associations' workshop,

presenters from Western Australia, New Zealand, USA and Romania demonstrated how increased awareness has led to a greater demand for services and how their associations have addressed this change.

The conference drew to a close with the World Health Organization (WHO) and ADI setting out the Kyoto Declaration – an action plan for dementia. The challenge now is to put this into action.

As in previous years, the social events featured highly in making the conference such a memorable event. ADI celebrated its 20th anniversary with a birthday party where Brian Moss, ADI's first chairman, cut the birthday cake and Harry Cayton led 'The history of ADI in a hurry' – a retrospective drawn from memories of people who have been involved with ADI since its formation. Entertainment was provided by the guests themselves as they took to the stage for karaoke! The gala dinner was also a night to remember as delegates networked socially in between traditional Japanese singing and dancing.



Simultaneous translation at all sessions meant that national and international delegates could share and learn from one another



Brian Moss cuts ADI's birthday cake alongside Henry Brodaty and Nancy Lombardo who were all present at ADI's first meeting in October 1984



Walk around the world – the exhibition hall featured displays from AAJ's 42 chapters and over 30 associations from around the world



Virginia and Wayne Bell, who have attended every ADI conference since 1989, with Japanese dancers at the gala dinner



Representatives from Alzheimer associations in the Asia Pacific region celebrate ADI's 20th anniversary

## The Stroud Series Symposia

# Understanding quality of life

**In dementia, quality of life might be defined as what really matters to people with dementia and their carers. It is the true goal of intervention and is what should really matter to policy makers and researchers.**

With this in mind, a small team – comprising Barry Gurland, Sube Banerjee and Nori Graham – set up the Stroud Series Symposia, a joint collaborative effort of the Stroud Center for the Study of Quality of Life, ADI and the Institute of Psychiatry. The trio have been working together for some years now collecting a series of narrative insights from people with dementia and carers. The symposia have become part of ADI's annual international conference and narratives have been gathered from North and South America, Europe, the Caribbean and Asia.

To date, workshops have been held during the last five ADI annual conferences. Themes have explored:

- Nature of quality of life
- What improves/reduces quality of life
- Actions promoting/impeding quality of life
- The carer/person with dementia relationship
- Relationship between choice and quality of life for people with dementia and family caregivers.



**Quality of life is a concept that is rather difficult to define but one that is intuitively understood**

The workshops are aimed at improving the quality of life for people with dementia and carers. Their focus is not to develop ways of measuring quality of life but instead to find ways of understanding quality of life in dementia. The rationale for the series came from the need to develop a cross-national understanding of what determines good and bad quality of life in dementia, and what can improve quality of life in dementia, and develop a framework with which to judge services and policy for people with dementia.

The workshops are spontaneous in spirit and participants are encouraged to contribute verbal and written statements. All contributions are recorded and combined with previous data workshops. So far, 252 contributions of text have been received.

Analysis of transcribed text from the first four workshops highlighted **education, touch, love, communication, humour** and **choice** as important elements of quality of life in dementia. The themes that have emerged are subjective and do not correspond to the disease progression, but have

illustrated the inter-dependence of quality of life for the carer and person with dementia.

Practical actions that can promote or inhibit quality of life in dementia to have come out of the sessions include statements such as:

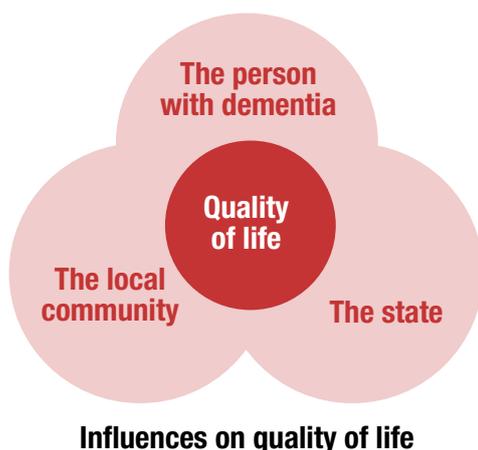
*'My great problem was getting professionals to LISTEN to me'*

*'Now I know that my quality of life is important and is directly linked with my husband's quality of life'*

*'When I am exhausted, depressed, emotionally-drained, suppressing my irritation and not being able to respond in the usual way to verbal abuse and false accusations, I find it very difficult to be patient, tolerant and understanding.'*

The success of the Stroud Series Symposia and the growing need to better understand quality of life has led to the development of the Stroud Symposia website [www.stroudsymposia.org](http://www.stroudsymposia.org) to be launched on 1 January 2005.

The website has been designed to make the growing pool of insights accessible to as many people as possible and will allow information to flow directly from consumers to consumers. The website is intended to be a dynamic one and users will be able to submit their own personal experiences to the site. In addition, new narratives will continue to be collected at future interactive symposia and by correspondence.



**1 January 2005**

**Launch of the Stroud Series Symposia website at [www.stroudsymposia.org](http://www.stroudsymposia.org)**