



Alzheimer's Disease  
International

March 2011  
Volume 21 No.1

# Global Perspective

A newsletter for Alzheimer's Disease International: The International Federation of Alzheimer's Disease and Related Disorders Societies, Inc.

## Recognition for people with dementia

In November 2010, Peter Ashley, long-time advocate for people with dementia across the world, was awarded an Honorary Masters from the University of Worcester in the UK.

Peter, who was diagnosed with Lewy body dementia in 2000, received the award from the University's Institute for Health and Society for his contribution to the field of dementia and therefore adding to the wellbeing of those in the UK.

Peter has been an Ambassador for Alzheimer's Society in the UK and worked closely with Alzheimer Europe in the past as well as attending numerous ADI events and acting as a spokesperson at countless

opportunities. He is also a member of the steering committee of the University of Worcester's Association of Dementia Studies, overseen by Prof Dawn Brooker.

Prof Brooker commented when Peter was presented with his degree: 'We welcome a pioneer campaigner in ensuring that those living with dementia get their voice heard, a committed patron who, despite his own condition, has done so much to improve quality of life in areas often overlooked.'

Peter was awarded his masters alongside UK newsreader John Suchet, who recently spoke openly about caring for his wife, Bonnie, who was diagnosed with dementia in 2006.

**PETER ASHLEY  
UK**



**Peter Ashley was diagnosed with  
Lewy body dementia in 2000**

**JAMES MCKILLOP  
SCOTLAND**



**James McKillop has spoken  
openly about his experience of  
living with dementia**

On 31 December 2010, the New Year Honours List of the Order of the British Empire was announced and ADI were pleased to learn that James McKillop, a founding member and former Chairperson of the Scottish Dementia Working Group, had been appointed a Member of the British Empire (MBE) for his voluntary services to people with dementia in Scotland.

James, along with his wife Maureen, has spoken at numerous dementia-related events across the world, sharing his experience of living with dementia, in particular the emotional effects it has had on his family and professional life.

Following the announcement of the honour, Henry Simmons, Chief Executive of Alzheimer Scotland said, 'James is a true inspiration to us all: using his own experiences of dementia to make a huge difference to the lives of countless others who have the illness. James and the Scottish Dementia Working Group have brought a vital new perspective of dementia to health and social care professionals, politicians and the media - their impact cannot be underestimated.'

James and Maureen will attend the awards presentation later in the year where a member of the royal family will present James with his MBE.

*ADI would like to congratulate both Peter and James on their well-deserved awards and look forward to continuing to work with them and learn from their experiences in the future.*



## 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 Friday 29 April 2011.

### Secretariat

Alzheimer's Disease International  
64 Great Suffolk Street  
London  
SE1 0BL  
Tel: +44 (0)20 7981 0880  
Fax: +44 (0)20 7928 2357  
Email: [info@alz.co.uk](mailto:info@alz.co.uk)  
Web: [www.alz.co.uk](http://www.alz.co.uk)

## Join us on Facebook!

facebook

ADI now has an official Facebook page and we would like you to join us! You can find us at [www.facebook.com/alzheimersdiseaseinternational](http://www.facebook.com/alzheimersdiseaseinternational) to keep up to date and join in with the latest ADI, member and dementia-related news and comment from around the world.

## Editorial

### Marc Wortmann, Executive Director



The worldwide dementia movement is coping with growth. The growing number of people with dementia and increased awareness leads to higher demand from the public and those who need care and support. More, better and earlier diagnosis means more work for us as associations! Alzheimer associations are approached more frequently and they cannot always deal with all of the requests. This is hard to understand for people who have written books or started exciting projects, but it has to do with capacity and organisational limitations.

Many organisations are struggling with their structure. I hear it from many of our members. Do we need more branches or chapters to respond to the needs and what are their roles and size? The same applies for ADI. We have greatly increased the content in *Global Perspective* compared to five years ago and we are getting more and more requests, invitations, plans, books and other initiatives. The good news is that people now come to us to help with the fundraising! Still, we can only handle a few things at the same time and have to say no to many nice projects.

As a result, a number of our members have asked us to review our structure and establish regional groups within ADI all around the world. This is not an easy task as different parts of the world are in different stages of development, but we will respond to it and start discussions at the conference in Canada in March.

I look forward to seeing many of you in Toronto!

## Events

### 2011

26 – 29 March 2011  
**26th Annual International Conference of Alzheimer's Disease International**  
Toronto, Canada  
Tel: +44 870 458 4171  
Fax: +44 870 442 9940  
Email: [adi2011@mci-group.com](mailto:adi2011@mci-group.com)  
Web: [www.adi2011.org](http://www.adi2011.org)

17 – 20 May 2011  
**Alzheimer's Australia 14th national conference**  
Brisbane, Australia  
Tel: +61 732 551 002  
Fax: +61 732 551 004  
Email: [info@alzheimers2011.com](mailto:info@alzheimers2011.com)  
Web: [www.alzheimers2011.com](http://www.alzheimers2011.com)

16 – 21 July 2011  
**Alzheimer's Association International Conference on Alzheimer's Disease (AAICAD)**  
Paris, France  
Tel: +1 312 335 5790  
Email: [icad@alz.org](mailto:icad@alz.org)  
Web: [www.alz.org/icad](http://www.alz.org/icad)

6 – 9 September 2011  
**International Psychogeriatric Association 15th International Congress**  
The Hague, The Netherlands  
Tel: +1 847 501 3310  
Fax: +1 847 501 3317  
Web: [www.ipa-online.net](http://www.ipa-online.net)

6 – 8 October 2011  
**21st Alzheimer Europe Conference**  
Moscow, Russia  
Tel: +35 229 7970  
Fax: +35 229 7972  
Email: [info@alzheimer-europe.org](mailto:info@alzheimer-europe.org)  
Web: [www.alzheimer-europe.org](http://www.alzheimer-europe.org)

18 – 20 October 2011  
**V Congreso Iberoamericano sobre enfermedad de Alzheimer**  
Havana, Cuba  
Email: [scual@informed.sld.cu](mailto:scual@informed.sld.cu)  
Web: [www.alzheimercuba.com](http://www.alzheimercuba.com)

20 – 23 October 2011  
**Seventh International Congress on Vascular Dementia**  
Riga, Latvia  
Tel: +41 22 908 0488  
Fax: +41 22 906 9140  
Email: [vascular@kenes.com](mailto:vascular@kenes.com)  
Web: [www.kenes.com/vascular](http://www.kenes.com/vascular)

9 – 11 November 2011  
**14th Asia-Pacific Regional Meeting of ADI**  
Bangkok, Thailand

### 2012

7 – 10 March 2012  
**27th Annual International Conference of Alzheimer's Disease International**  
London, UK  
Tel: +44 870 458 4171  
Fax: +44 870 442 9940  
Email: [adi2012@mci-group.com](mailto:adi2012@mci-group.com)  
Web: [www.adi2012.org](http://www.adi2012.org)



# Carer's story from Iran

**Faraneh Farin**

**E**ight years ago, my father died and in no time my mother was diagnosed with Alzheimer's disease. It was a frightful shock to me, as a nurse, and my mother who was just 62 years old.

At the time, my mother was living in the north of Iran. All of her children lived within 200 kilometres of her hometown. Distance became a challenge for her caregivers as her doctor had stressed on keeping her, as long as it was possible, in the same environment.

As time elapsed, there was no other choice than to hire a caregiver. My brother also stayed nearby. Maybe she acquired more peace in this arrangement staying with her old time memories. We shared the tasks of care giving, doctor's visits, reports of progress of the disease and a care schedule being it my duty to provide. All of us shared the health and care costs, visited her regularly and replaced the primary caregiver whenever she was off duty.

During the second year of her illness, she deteriorated rapidly; wandering, memory loss and incontinence were some of the obstacles, which prevented her from performing



**Faraneh Farin's mother, who had Alzheimer's disease, and father**

even simple tasks. It was time for another major decision. Mother had to be moved nearer to her children, accessing better care from them.

At first, she seemed physically and mentally improved but gradually the good effects vanished. She became remarkably slow and lost. She was unable to express herself even in short sentences and just uttered single words. Gradually she could not recognise people or her children. Disorientation of time and place added to her numerous problems.

In a short time, she became totally dependent and somehow cut off from her environment. We now had only one way to connect to her, holding her hands, hugging her and showing her our love.

We had a regular schedule to spend some time with her during the day – reminiscing by looking at the old photos, singing folkloric songs, talking about her good old recipes and going for walks. This path lasted four years.

During the third stage of her journey, she lost her cognition and mobility but her hands still felt the same warmth and love. Even during this stage she continued to be our mentor. She demonstrated to us that even in the impasse of life, it is only with power of love that one can survive. It is now a few months since we lost her.

The devastating agony of Alzheimer's disease engulfs many parents and their children who bear the stress of being a caregiver. Indeed, the experience of the Alzheimer's journey changed my perception. Hence, I now work for Iran Alzheimer's Association, helping the people who need to be helped desperately.

## 'Three conferences in one'

**The 27th International Conference of Alzheimer's Disease International will take place in London, UK, 7 – 10 March 2012**

The event, co-hosted with Alzheimer's Society, promises to offer three conferences in one under the theme *Science, Fact, Fiction*, and will cover the many facets of dementia worldwide.

London will be an exciting city in 2012 and, by March, final preparations for the Olympics, which will take place close to the conference venue just a few months later, will be well underway.

We do hope that you will join us in London for this conference, which will have something for everyone. For more information about the conference and to register to receive regular updates on abstract submission, the conference programme and registration visit the conference website at [www.adi2012.org](http://www.adi2012.org)



# Caring for my wife with dementia – as a doctor and as a caregiver

**Dr Yoshio Miyake, Japan**

(TRANSLATED BY SHIVANI NANDI)



**Yoshio Miyake and his wife**

On 7 July 2008 my wife Yoko, who was 54 years of age at the time and had been complaining of tiredness and lack of appetite, found herself suddenly unable to walk and had to be taken to the hospital by an ambulance. She lost consciousness in the ambulance and had a convulsive seizure. The hospital that she was taken to diagnosed her condition as non-herpetic limbic encephalitis of rare and unknown etiology.

To my shock and puzzlement, in the almost six months of her hospitalisation, she developed dementia from the after effects of the encephalitis. Once she was discharged from the hospital, I took early retirement from my work as a physician and started providing full-time home care for her.

Yoko forgot what she had heard a minute or two before and her long-term memory was fragmented. Most of the time she does not recognise me and wanders away from the house saying she is going to go back to her, far-away, maternal home. These memory problems would be accompanied

by intense emotional changes leading to outbursts of anger and symptoms of dementia being played out all at once.

As a geriatrician involved in dementia care and interacting with people with dementia and their families for over 30 years, the thought that in the not-too-distant future one of us would go on to develop dementia did come to me, but never had I imagined that my wife would develop dementia at such an early age as a result of encephalitis. For the first time, after starting to take care of my wife with dementia, I came to realise that even though there wasn't any great change regarding what I had said or written or thought about prior to her becoming ill, caring was an exceedingly difficult task and not just pretty words.

Even though I understood that it was her illness that made her behave thus, there were times when I would find her savage words and irrational behaviour unbearable and would find myself hitting out or kicking at her. Day by day, as I watched this hardly recognisable person that she had turned into, I also thought of ending our relationship together. Yet, through such times, I have a conscious renewal of my feelings of gratitude toward the kindness of people.

At first, the very first person that I, as a doctor, consulted regarding my wife's rare encephalitis was Prof Nakamura, one of the leading neurologists who also serves as an advisor to Alzheimer's Association Japan. When he heard the name of the disease he told me that he was horrified. I believe that it is indeed a horrifying disease.

Before she was released from hospital, Yoko was able to get certification of long-term care needs from the public long-term care insurance and, a month after her release, she was able to start using day-care services. Once the care manager understood her condition she was able to recommend a small dementia-specific care centre near our house and this proved to be of great help to me. The care giving level of the staff was indeed very good. While Yoko was being cared for at the day-care centre I was able to rest and have some time on my own.

There were times when I was totally at a loss due to Yoko's "wandering". I am indebted to the policemen who uncomplainingly found her each of the four times that she went missing and my heart is full of gratitude toward them. Also, I had explained her illness to my neighbours beforehand, so that when at times she would scream "help me" in a loud voice in the middle of the night, they were kind enough to understand the situation. Furthermore, with conversation being fragmented with my aphasic wife, when I started to feel the need for a normal conversation, two friends from the Shiga prefecture and Mrs Saruyama, a former president of a chapter of the Alzheimer's Association Japan, started to visit regularly as a group and provided me with much needed relief. I have also received words and letters of encouragement from Daisy Acosta, Chairman of ADI, and other friends from overseas.

I have begun to think that, three decades after the founding of the Alzheimer's Association Japan, the seeds we planted have begun to germinate...



# Members' forum

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

## Dementia newsflash

In this new feature for 2011, we bring you some of the latest dementia news from members across the world and the ADI website newsfeed.

### Bangladesh

Azizul Haque, Secretary General of the Alzheimer Society of Bangladesh, was awarded an International Excellence Award in 2010 from the University of Stirling in the UK.

### The Netherlands

Alzheimer Nederland, in partnership with the National Missing Persons Bureau, is lobbying for the use of a GPS chip to detect people with dementia who go missing.

### Malta

A recent Alzheimer Europe study has found that Malta is one of the only European Union member states not to offer financial assistance to cover medication for people with dementia. The current cost of medication in the country is around €150 per month.

### Venezuela

Fundacion Alzheimer de Venezuela has published a new book, developed by their President Mira Josic de Hernandez, containing more than 150 recipes using ingredients that are known to be good for the body and the brain.

### Europe

The European Parliament has called upon the European Commission and the Council of Ministers of the European Union to recognise dementia as a health priority within the region by developing a European Action Plan.

To see the latest news, visit [www.alz.co.uk](http://www.alz.co.uk)

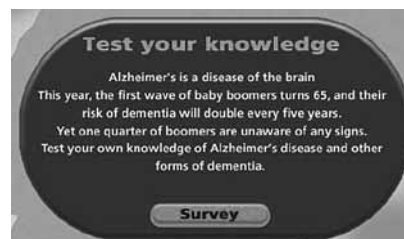
## CANADA

### Unprepared for dementia

One in four people completing an online survey conducted by the Alzheimer Society of Canada could not name a single symptom of dementia. Only one in two identified memory loss as a sign.

The 1,006 respondents between the ages of 45 and 65 – the age group most likely to take up a role as family carer – appeared to be very unprepared for dementia. One third of all respondents had been touched by dementia in some way, but were only slightly more informed than those with no experience of dementia.

The Society hopes that the results will assist their call for a national dementia strategy to ensure that Canadians are better educated about dementia, and to develop a number of policies to improve support for carers, care facilities, early diagnosis and research.



For more information about the Alzheimer Society of Canada and their work visit [www.alzheimer.ca](http://www.alzheimer.ca)

## INDIA

### Memory Walk 2011

On 9 January, the Calcutta chapter of the Alzheimer's and Related Disorders Society of India (ARDSI) hosted their Memory Walk 2011 to raise awareness and give a voice

to people with dementia and their carers.



Over 250 participants joined the walk, including students, well-known personalities and representatives from fellow associations. Following the walk, the Dementia Solidarity Congregation adopted a Citizens' Charter on Dementia Solidarity, encouraging dementia to be made a national health priority. The *Dementia India Report*, highlighting the current scale of dementia, was formally launched during the event.

The Memory Walk was such a success, ARDSI Calcutta will now host it annually. To find out more about ARDSI and ARDSI Calcutta visit [www.alzheimer.org.in](http://www.alzheimer.org.in)

## DENMARK

### National plan not enough

Alzheimerforeningen have welcomed the introduction of the Danish government's action plan on dementia, announced in December.

The proposal is for 20 million dollars to be allocated to examination, diagnosis and care over the next four years. The government has also pledged to improve respite and relief services. A survey will be sent out to those in need of such services as a first step.

However, the association is keen to highlight the plan's lack of urgent decision-making and specific proposals required to fully address

*continued page 8...*



Member of an art group coordinated by Zimbabwe Alzheimer's and Related Disorders Association



TADA Chinese Taipei's Choir of Wisdom performed at the Asia Pacific regional conference in 2008



An entry for the ADI Photography Competition by Carmen Barreto, Brazil

## Arts and dementia

**With a growing awareness of the benefits of various forms of therapy for people with dementia, Alzheimer associations worldwide have increased their use and promotion of a wide variety of the arts in caring for people with dementia**

Using the arts in caring for people with dementia is not a new phenomenon. In 1996, Alzheimer's Association Korea opened the Songpa Senior Welfare Services Centre, where people with dementia could choose from fifty practical activities, including traditional Korean dancing and calligraphy. Arts and crafts now play a role in many day care centres run by Alzheimer associations, including Hong Kong Alzheimer's Disease Association, The Alzheimer Society of Ireland and Iran Alzheimer Association. The Alzheimer's Disease Association of Singapore created an arts room at their New Horizon Centre and dedicated an hour each day to art.

Many associations have developed their own art programmes. Zimbabwe Alzheimer's and Related Disorders Association hosts weekly art groups for people with dementia, with exhibitions of their work. ABRAZ in Brazil also hosted an exhibition of artwork by people with dementia in 2005, which was a great success. The Alzheimer Society of Canada have developed a section of their website, entitled *Creative Space*, which acts as a place where people affected by dementia can express their experiences through creative writing or artwork. Muistiliitto ry in Finland collaborated with the Finnish

National Art Gallery to create a multi-sensory tour of the Gallery in 2008.

The Scottish Dementia Working Group, run by people with dementia, has conducted a number of arts-based activities, including the production of a calendar using photographs taken by members of the group. In 2007, they produced a film detailing their work.

World Alzheimer's Day has been a useful platform for national Alzheimer associations to facilitate art activities for people with dementia. A number of musical events and film screenings particularly for people with dementia and their carers have recently taken place in Sri Lanka, Romania and Belgium and the live events often feature performances by people with dementia.

Conferences give people with dementia and carers the opportunity to share their experiences – and can also showcase artistic work. During ADI's 2004 International Conference in Japan, a lady with dementia sang at the Gala dinner. In 2008, TADA's Choir of Wisdom performed during the opening of the Asia Pacific regional meeting. The Choir of Wisdom is a part of the association's School of Wisdom for people in the early and moderate stages of dementia, helping people

with dementia gain strength by expressing themselves through exercise, art and music.

During the ADI International Conference in 2010, Ninoslav Mimica from Alzheimer Disease Societies Croatia detailed his experience of meeting a person with dementia and his wife during one of the association's monthly meetings at their Council centre. This man had been advised to attend a well-respected day care centre in Zagreb and reported that, while he was at the centre, occupational therapists provided person-centred rehabilitation, which it was hoped would assist him with behaviour disturbances. Ninoslav explained, following one man's experience of art therapy, that 'he hadn't painted pictures before developing Alzheimer's disease and everybody, including his wife, was surprised by his talent. Also, while painting he was calm and satisfied.'

At the heart of this work is the willingness to offer a more person-centred care approach. Art is a means of self-expression and allows people with dementia the freedom they need to continue to live a good quality of life. Whether a newfound hobby or a return to one discarded in earlier life, the positive effects of artistic activity are evident across the world.



# A Nice art project

By Valerie Lafont and Cathy Greenblat. Photographs by Cathy Greenblat, France

The management of diseases of memory cannot be limited to research on pharmacological treatments and methods for early diagnosis. The fight against the disease should also entail adaptation of the environment, and promotion of the sense of dignity and a positive vision of ageing. It is essential, then, to engage in multidisciplinary activities that address both people with dementia and their families. Such activities should focus on improvement of their quality of life, integration of people with dementia into the society, and creating a destigmatised image of them.

These aims are part of the France Alzheimer plan (2008–2012), which promotes non-pharmaceutical treatments, care for both people with dementia and their carers, and initiatives that help to change the perceptions of the general public about Alzheimer's and related disorders and about ageing.

In a growing number of cities in the world, cultural sites have opened their doors to those with cognitive challenging disorders. Programmes at the Louvre in Paris and the Museum of Modern Art in New York, for example, feature structured art experiences for small groups of such persons. Under a policy of openness to cultural sites for people with various disabilities, the city of Nice and the Center for Memory Research and Resources (the CMRR) of the hospital network of Nice established a collaborative project.

In the spring of 2010, seven municipal, state and national museums participated in the pilot programme, each hosting a one and a half hour group visit by an average of 12 people with dementia and family members from the CMRR and several day programmes. Structured presentations, encouraging participant interaction, were



presented by museum personnel working with teams of professionals from the CMRR. This social, cultural and artistic project was nested in the larger clinical experience provided by and evaluated by the CMRR staff. Cathy Greenblat, Artist in Residence at the CMRR, documented the programme photographically.

As a result of the enthusiastic responses by all concerned, the municipality agreed to continue and expand the programme in 2011. The mayor and city council invited and arranged a one-month exhibition of 24 of Cathy's photographs in the entrance hall of main library of the city, where an announcement was made on World Alzheimer's Day 2010 of the larger programme to come. The first partners were the museums of Nice; in the enlarged artistic programme the museums will continue to be of importance, but other associations such as the Music Conservatory, the Opera, the Theatre National de Nice,

and the Philharmonic Orchestra of Nice will participate as well.

The originality of the programme is, in its success, helping a municipality bring to bear the resources necessary to improve the integration of these people with dementia into their immediate environment: their city.

We believe that similar collaborative programmes between groups serving the Alzheimer's community and municipal governments' cultural offices can be established in many other places.

*An exhibition of Cathy Greenblat's photographs will be held at Baycrest Hospital, Toronto, 27 March to 25 May with scheduled tours on 27 and 29 March. For more information see details at the ADI conference or email [info@alz.co.uk](mailto:info@alz.co.uk)*

Members Forum continued from page 5 ...

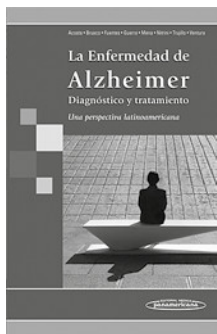
dementia issues. The plan also pays little consideration to the economic demands dementia makes. It is felt that the 5 million dollars per year will be nowhere near sufficient.

Alzheimerforeningen have expressed their willingness to work closely with the government on implementing the proposals – particularly the review of the strict current health law on consent of treatment, which means that people with dementia often do not receive the treatment they need.

For more information on Alzheimerforeningen's work visit [www.alzheimer.dk](http://www.alzheimer.dk)

## LATIN AMERICA

### Diagnosis and treatment



A booklet aimed at broadening the knowledge of health professionals and the general public in the Latin American region is set for release this month.

*La Enfermedad de Alzheimer. Diagnóstico y Tratamiento: una Perspectiva Latinoamericana* (Alzheimer's Disease. Diagnosis and Treatment: A Latin American Perspective) is authored by a collective of renowned researchers from Argentina, Brazil, Chile, the Dominican Republic, Mexico, Peru and Uruguay.

The 119-page booklet, which can be used as a pocket guide, contains detailed yet easily understandable information about various areas of treatment and diagnosis, including clinical and diagnostic evaluation, drug and non-pharmacological therapies, physiopathology, patient care and epidemiological data.

The publication will be widely available from March.

## SOUTH AFRICA

### Dementia: a hidden disease

A local study into dementia in the urban black population in South Africa has found its prevalence to be nearly three times higher than previously estimated. The pilot study, conducted by researchers at the University of the Free State

and funded by Alzheimer's South Africa, looked at a test group of 250 households in the township of Mangaung. Six per cent of elderly residents showed possible age-related dementia and are now undergoing clinical testing.

The coordinator of the study, Rikus van der Poel, explained that until now there had been no purpose-built

## UK

### Drugs for mild dementia approved at last

After years of campaigning, Alzheimer's Society in the UK was pleased to learn that the National Institute for Health and Clinical Excellence (NICE) for England and Wales had found evidence of the benefits of drugs on those in the mild stage of dementia.

Five years after NICE declared that they should not be prescribed to those experiencing the early symptoms of dementia, donepezil, galantamine and rivastigmine have now been considered to be both beneficial and cost-effective. NICE's initial decision to only provide this medication to those in the moderate stage of dementia was a result of concern over the benefits and positive long-term effects it would have on the person's quality of life. NICE have now declared that they are confident of these benefits.

Clive Ballard, Director of Research at Alzheimer Society, said of NICE's decision: 'If this guidance is issued, doctors will no longer have to watch people deteriorate without being able to treat them.' It is reported that the equivalent of NICE in Scotland may follow this decision.

NICE also announced that there is a possibility of a fourth drug, memantine, being made available to those with more advanced dementia.

The screenshot shows the Alzheimer's Society website interface. At the top, there are links for Accessibility, Site map, Mobile, Shop, Basket, and Advanced search. The main header reads 'Alzheimer's Society' with the tagline 'Leading the fight against dementia'. A 'Donate now' button is visible on the right. The 'Dementia related FAQs' section is highlighted, with a list of questions and answers. Below this, there are three featured questions with images of people: 'About dementia', 'Symptoms & Diagnosis', and 'Living with dementia'. A 'Got a question about dementia?' section is also visible at the bottom left.

Alzheimer's Society has launched a new Frequently Asked Questions section of their website. This can be found at [www.alzheimers.org.uk/faq](http://www.alzheimers.org.uk/faq)



prevalence study on dementia in South Africa. 'It requires an enormous amount of translation work and access to communities. It is under diagnosed because there is a lack of awareness and our system focuses on primary health needs.'

Professor Malan Heyns, the chief researcher for the project, says the choice of the Mangaung township was 'merely a matter of convenience' as it is close to the university. Heyns says he 'wouldn't speculate' about a link between urbanisation and dementia as many of those in Mangaung had migrated from rural areas: 'I believe that what we will find in the urban areas we will find in rural ones, too.'

The lack of awareness in South Africa is thought to result from a belief that Alzheimer's disease mainly affects white people – or that it is a normal part of ageing. It is also suggested that there is reluctance in the country to seek a diagnosis or attend to any ailment that could involve mental illness.

The research group hopes to secure funding for a larger test group of 2,000 households.

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## USA

### Alzheimer strategy

On 4 January, President Obama signed the National Alzheimer's Project Act into US law.

The Act represents a very important step towards a coordinated national strategy for the country and was a result of the hard work of the Alzheimer's Association and recommendations of the Alzheimer's Study Group, an independent panel formed to evaluate the government's current efforts in the area.

It is believed that the final result of this Act will be the creation of a national strategic plan for the country and will also see the development of an inter-agency

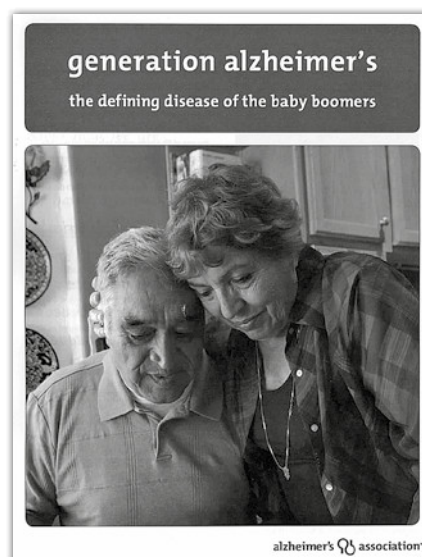
council that will work alongside the Secretary of Health and Human Services, addressing the needs for improvements in care, research and support.

Harry Johns, CEO of the Alzheimer's Association, highlighted the urgent need for implementation of a national strategy, 'The fact that Alzheimer's is the only one of the top 10 causes of death in the US without a way to prevent, cure or even slow it underscores the critical need for the swift, aggressive implementation of this legislation.'

### Baby boomers beware

In response to the increasing number of people with dementia in the country, as those from the 'baby boom' period following the Second World War reach the age of 65, the Association have released a report entitled *Generation Alzheimer's: the defining disease of the baby boomers*. The report describes how more than 10,000 individuals across the country will reach the age of 65 each day and, as they age, the numbers of people with dementia are set to increase at an alarming rate.

To view the *Generation Alzheimer's* report and find out more about the National Alzheimer's Project Act visit [www.alz.org](http://www.alz.org)




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## SOUTH KOREA

### War on Dementia

South Korea has proven to be a world leader in dementia care and awareness raising following coverage in the *New York Times* in November 2010 of the country's far-reaching efforts.

In a country where the over-65 population is predicted to double from 7% in 2000 to 14% in 2018, the government has recognised the need for action and, working closely with Alzheimer's Association Korea, has developed initiatives to fight the country's 'War on Dementia'.

One of these programmes is to train members of the public to become 'dementia supporters' by offering activities that will allow them to recognise the symptoms of dementia and provide a good standard of care. As part of this, children are invited to the Dementia Experience Centre where they take part in ageing simulation exercises, are given a presentation on dementia and learn how to give hand massages. College students are shown a 3D video following a person with dementia. Other initiatives include intergenerational programmes, iron-on identification numbers for people with dementia to be used when wandering occurs, and a 'silver industries' project which involves businesses opting in and producing products to make everyday living easier for people with dementia and their carers.

The creation of centres specifically for diagnosing dementia, more nursing homes and day care services have also shown the government's commitment to the cause. The government has also developed a long-term care insurance system to fund these initiatives. ADI would like to congratulate Alzheimer's Association Korea for their continued hard work on behalf of people with dementia and their carers in South Korea.

## ■ Living with dementia

# A review of the ADI meeting from a mind touched by dementia

In the lead-up to this year's conference, **Helga Rohra** from Germany, who lives with Lewy body dementia, speaks about her participation at ADI's 25th annual International Conference in Thessaloniki, Greece in March 2010

Our registration for the international meeting took place in a quite luxurious lobby of the Grand Hotel, Thessaloniki.

From the very moment you are welcomed you can feel the importance of the meeting, everything is organised up to the smallest detail. In the forthcoming days, well-known neurologists, carers, and all kind of experts in the field of Alzheimer's and related forms of dementia will debate, present new figures and inform the audience about the standings worldwide.

There are many workshops, satellite symposiums, and exhibitions. You are amazed by all those people who represent Alzheimer associations worldwide. You get the feeling of being welcomed by a big family!

All those present want to get more information, want to get answers to questions troubling them about the disease. Finally, they want to get involved and believe firmly in the strength of solidarity in facing dementia.

You realise how much is invested in research, you feel the endeavour of people's work, and you learn about new approaches or ways of dealing with dementia in other countries.

You are grateful to the people who invited you. Of course you speak up, you share with others your daily experience of living with dementia.

You learn about the importance of nutrition, about physical and mental



exercise and not to forget social aspects and one's own approach in dealing with the disease.

I am wearing a badge. My name is written on it as well as that of the Alzheimer association in Germany – Munich, which I belong to. It is a special feeling overwhelming me: I know I am part of the big Alzheimer family.

There are many talks with all of the other people affected by dementia and imagine they are all people like me, like you. Some have been living with a diagnosis for some years.

There is a common fate. We are all united in our dementia. I never feel lost, together we are strong. This wonderful feeling accompanies me in all sessions, no matter whether it's the workshops or the nice evenings.

We, those touched by dementia, know it is important to speak up. We have to be respected, we are not only experiencing impairment, we can still do a lot. Just give us a chance, listen to us.

No decision about us without us! A message I stood up for in the workshops.

You know, I felt very strong all of those days. I strive for the "mission dementia".

The ADI meeting had a very significant title: *Dementia – making a difference*. How true – yes, this difference we want to emphasise in our own countries. Believe it or not, it is a new consciousness of people affected by dementia.

I myself am very confident. We ourselves have to speak up. It isn't sufficient to talk about statistics or to interpret computer animations of our brain. Please don't forget our own self, don't always ask about deficiencies, see our still existing abilities. Talk to us!

I especially remember one workshop: "Ways of embedding people with dementia in social decisions". I know together we are able to change ways of dealing with people with dementia. We are all a big family!

I learned about the power of solidarity in dementia – a feeling that is still with me today.

We go ahead and look forward to saying "hello" and not "good-bye" in Toronto in March 2011.

## ■ Research update



### Research into the prevention of Alzheimer's disease: are we in danger of losing sight of the forest for the trees?

**Professor Kaarin J Anstey, Dementia Collaborative Research Centre – Early Detection and Prevention & Centre for Mental Health Research, Australian National University**

The National Institutes of Health published a significant report on the prevention of Alzheimer's Disease in April 2010<sup>1</sup>. This was the most comprehensive review of the evidence on risk factors for Alzheimer's disease to date and is an invaluable resource for anyone wanting to know the findings of current longitudinal studies. The publication was timely because the field has now reached a stage where many longitudinal studies have published their results and these can be pooled together.

The review identified diabetes, the epsilon 4 allele of the apolipoprotein E gene (APOE e4), smoking, and depression as factors that are consistently associated with an increased risk of Alzheimer's disease. Engagement in physical and cognitive activity were consistently shown to decrease the risk of Alzheimer's disease. Since the publication of the report, statistical modelling has demonstrated enormous benefits could be achieved by reducing the incidence of risk factors associated with dementia.

However, the publication has caused a lot of debate, not because of the actual contents and findings of the reviews of risk factors, which were rigorously conducted, but because of the significance attached to the findings. The authors concluded that "The current research on the list of putative risk or protective factors is largely inadequate to confidently assess their association with Alzheimer's disease or cognitive decline. Further research that addresses the limitations of existing studies is needed prior to be able to make recommendations on interventions."

Perhaps the main reason for this confusing conclusion to what is otherwise an outstanding report,

is the rating system used by the authors. This reserved a 'high' rating of evidence for findings based on randomised controlled trials. In fact, most putative risk factors for Alzheimer's disease are not amenable to randomised controlled trials. For example, it is not possible to randomly allocate research volunteers to a smoking versus non-smoking condition and then follow them up for 25 years to see which group has the greatest risk of Alzheimer's disease. Likewise, it is not possible to conduct such experiments on insecticide exposure, depression, anti-depressants, high blood pressure and so on.

For many risk factors there is plausible biological basis for their association with Alzheimer's disease, based on laboratory research and animal studies. In this respect the research in Alzheimer's disease does not differ from research in cancer epidemiology where putative risk factors that are not amenable to randomised controlled trials (e.g. exposure to polychlorinated biphenyls) are observed in longitudinal studies and their carcinogenic properties explored in animal models<sup>2</sup>.

The conclusion of the report really raises two important questions for our field. First, how should we determine the level of evidence for risk factors that are not amenable to randomised controlled trials? Second, to what degree should ethical, moral and pragmatic concerns be considered in addition to the available scientific evidence when making decisions about population-level prevention strategies involving low risk (or no-risk) interventions?

Decisions about funding interventions occur in a social context and involve wider considerations about cost, benefit and risk. If an intervention itself

is not harmful and has other public health benefits, is the risk (and potential cost) of not intervening greater than the risk of the intervention? Do we, in fact, have a moral obligation to trial interventions because of their potential to eliminate suffering?

Some commentators interpreted the overall findings of the report as summarised in the abstract to mean that there was no evidence that Alzheimer's disease is preventable. It is true that cause and effect were not demonstrated, but the term 'prevention' is understood differently when speaking about population-level prevention. From a population health perspective, reduction of risk has been shown to reduce population-level incidence of diabetes and heart disease. It is likely that a similar result will occur for dementia. In population-based research, prevention of incidence of a disease at the population level due to risk reduction is a realistic goal.

The stakes of not trying to prevent Alzheimer's disease are so high that we cannot afford to overlook any potential modifiable risk factors for Alzheimer's disease. We need to be careful to set appropriate benchmarks for considering evidence where randomised controlled trials are not possible.

*Note: The views expressed in this article are the views of its author and not necessarily those of the Australian Government.*

#### References

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## Obituary

### Jim Jackson



ADI was shocked and deeply saddened to learn of the sudden passing of Jim Jackson on 12 January at his home in Edinburgh, Scotland.

Jim initially became involved with ADI in the early 1990s as Chief Executive of Alzheimer Scotland – Action on Dementia and quickly began participating in the work

of ADI, frequently attending the annual International Conference and, in 1994, heading the Alzheimer Scotland team who hosted the event.

Over the years the reach of Jim's work increased and he developed strong relationships with a number of ADI's member associations including the Lanka Alzheimer's Foundation through their Twinning relationship with Alzheimer Scotland, the Polish Alzheimer's Association and the Romanian Alzheimer Society.

He was a true advocate of Alzheimer associations, particularly those in developing countries, and showed a real commitment to improving the lives of people with dementia and their carers around the world.

Since Jim's retirement from Alzheimer Scotland in 2008, he had continued to work on a number of

ADI projects, such as the Global Alzheimer's Disease Charter as a member of the advocacy working group, and more recently as co-author of the widely cited World Alzheimer Report 2009. His presence and involvement in the International Conference was ever increasing and he was due to co-ordinate a number of workshops and meetings during this year's conference in Toronto.

In true Jim style he had been for a run on the morning of his death. Upon his return home, he suffered a severe heart attack. ADI wishes to send the deepest of sympathies to Jim's wife, Jennie, their two children and all of his close family and friends. Jim will be greatly missed by so many around the world and a short event will take place to remember his work and dedication during ADI's Council meeting on Saturday 26 March in Toronto, Canada.

#### Some tributes from ADI members

*'Men like Jim Jackson never die. His vocation to serve others goes beyond death, and this is his legacy to all of us. This is how I prefer to remember him, and this is really the way I always saw him, with a big smile.'*

Daisy Acosta, ADI Chairman

*'The movement has lost a tireless advocate, with a sure sense of the priorities and the need for action, whether that be in Scotland, Europe, or more recently (for example with his marvellous contribution to the World Alzheimer Report 2009) at the global level. I have always admired and respected him as the very model of an effective leader of an action and advocacy-based NGO. May his example live on. His contribution will certainly be felt for years to come.'*

Martin Prince, 10/66 Dementia Research Group

*'We shall miss Jim, he gave us in Sri Lanka, so much hope in our convictions to serve. Let us not grieve, but rather applaud Jim's contribution to the Alzheimer's journey.'*

Tami Tamitegama, Sri Lanka

*'A few members of the Polish Alzheimer's Association, including myself, had a chance and a great pleasure to meet Jim for the first time at an ADI conference a long time ago and it seems that now a conference without his presence and great sense of humour, wisdom, his true involvement, passion, and readiness to talk openly with everybody, to solve problems, to analyse, to build, and to advise is absolutely impossible to imagine.'*

Mirka Wojciechowska, Polish Alzheimer's Association

#### 25 Years of ADI

ADI marked its 25th anniversary in October 2009 and a new publication, reflecting on the first 25 years of ADI's work, is now available. For more information about the publication please contact [info@alz.co.uk](mailto:info@alz.co.uk)



#### Faces of dementia

The theme for World Alzheimer's Day™ 2011 is *Faces of dementia*. On 21 September, ADI and national Alzheimer associations worldwide will be asking if you recognise the face of dementia while paying tribute to those who represent the faces of dementia in all parts of the world by working tirelessly to promote increased support and care for people with dementia and their carers. To find out more visit [www.alz.co.uk/WAD](http://www.alz.co.uk/WAD), where you can also read a report on the successes of World Alzheimer's Day 2010.