



**Alzheimer's Disease
International**

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Global Perspective

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

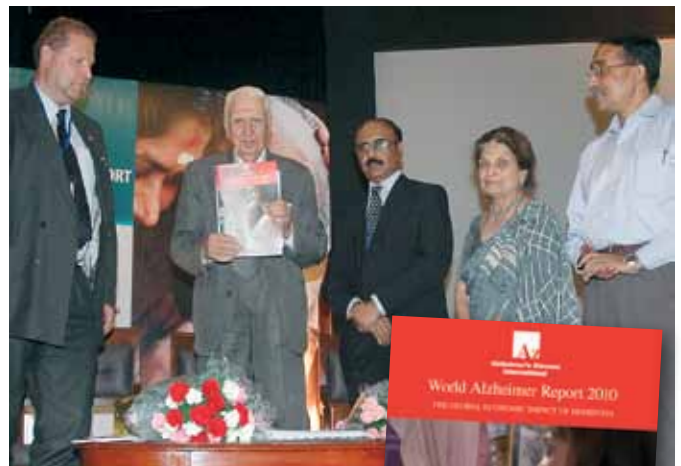
ADI releases landmark report

The global economic cost of dementia hit the headlines worldwide on 21 September with the launch of the World Alzheimer Report 2010. The launch was a monumental success for ADI on World Alzheimer's Day and raised an unprecedented amount of global awareness of dementia and ADI's work.

The report, authored by Prof Anders Wimo and Prof Martin Prince, provides the clearest, most comprehensive global picture yet of the economic impact of dementia and estimates the worldwide cost of dementia to be US\$604 billion, which is around 1% of the world's GDP. The report also contains important policy recommendations and urges decision-makers to improve policies and services.

Media coverage of the report extended to at least sixty-six countries across the world. Over 1,030 media reports resulted from the coverage on the day, making this ADI's largest media coverage to date.

Martin Prince commented, 'I suspect that this may be the biggest concentrated global coverage of a dementia-related story yet. Indeed, I doubt whether any disease advocacy group, with the possible exception of HIV/AIDS, has ever managed to achieve similar coverage.'



ADI and ARDSI representatives present the World Alzheimer Report 2010 at the launch event in New Delhi, India



continued on page 6



Join us in Toronto!

Only three months remain until ADI's 26th International Conference in Toronto, Canada, 26-29 March 2011.

Final preparations are now underway and ADI and the Alzheimer Society of Canada wish to extend an invitation to all people with dementia, carers, researchers, scientists, medical professionals and Alzheimer association staff.

Topics covered at the conference will include advocacy and the public health agenda, psychosocial research, scientific developments in Alzheimer's disease, lifestyle and prevention and dementia in indigenous countries. With such a broad range of subjects, there will be something for everyone.

Early bird registration for the conference ends on 14 January 2011. Your accommodation for the event can also be booked through the conference website.

A number of exciting excursions are also on offer, including a day trip to the majestic Niagara Falls, a Maple Syrup tour and a trip to the top of one of Toronto's most visible landmarks, the CN Tower.

To register and find out more about what promises to be an enlightening and enjoyable event, visit the website at the address below.

www.adi2011.org



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 28 January 2011.

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Editorial

Daisy Acosta, Chairman



We have reached the end of another successful year of the global dementia movement and what a year it has been!

The past few months have been a particularly exciting time for us. The launch of the World Alzheimer Report 2010 achieved a lot of much needed media coverage of dementia worldwide. I would like to thank all who helped in the production and promotion of the report. We couldn't have achieved these results without you and we hope that it will make a real difference to policy change and the care of people with dementia in all of your countries.

World Alzheimer's Day has, once again, played an enormous part in raising awareness of dementia. Congratulations to everyone who planned or was involved in any of the events taking place around the world. Our hard work is continuing to pay off!

I would like to thank all of our members and the individuals and other organisations around the world that work tirelessly alongside us for this hugely important cause. It has been a very successful year and we look forward to continuing our work with you in 2011. On behalf of ADI's board and staff, I would like to wish you all the best for the season.

Events

3 – 4 February 2011
6th International Pharmaco-Economic Conference on Alzheimer Disease (IPECAD VI)
London, UK
Web: www.ipecad.org

19 – 20 February 2011
2011 National Alzheimer Conference
Bucharest, Romania
Tel: +40 212 105 814
Fax: +40 212 122 702
Email: registration@alzcongres.ro
Web: www.alzcongres.ro

9 – 13 March 2011
10th International Conference on Alzheimer's and Parkinson's Diseases
Barcelona, Spain
Tel: +41 229 080 488
Fax: +41 227 322 850
Email: adpd@kenes.com
Web: www.ad-pd.org

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
Web: 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
Web: www.alzheimers2011.com

16 – 21 July 2011
Alzheimer's Association International Conference on Alzheimer's Disease (AAICAD)
Paris, France
Web: www.alz.org/icad

6 – 8 October 2011
21st Alzheimer Europe Conference
Moscow, Russia
Tel: +35 229 7970
Fax: +35 229 7972
Email: info@alzheimer-europe.org
Web: www.alzheimer-europe.org

18 – 20 October 2011
V Congreso Iberoamericano sobre enfermedad de Alzheimer
Havana, Cuba
Email: scual@informed.sld.cu
Web: 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
Web: www.kenes.com/vascular

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

CORRECTION Please note that the Seventh Vascular Dementia Congress will take place on 20-23 October 2011, not 2010 as mentioned in the previous issue of Global Perspective. We apologise for any inconvenience this may have caused.



A carer's story

Maureen McKillop, Scotland

A number of years before my husband James was diagnosed with dementia, our lives changed from being a happy family unit of Mum, Dad and four children, to a family which dreaded this man coming home from work, or even being around us.

He had become argumentative and aggressive. I was accused of all sorts of things. If I had gone out to a meeting and had gone in the car as it was raining, I got the third degree when I got home because my coat was wet. "How can your coat be wet if you went in the car, where have you really been?" There was nothing I could say to get through to him that I had to park the car and walk into the meeting room. Things got so bad that I went out less and less with my friends. It was not worth the hassle.

Just before the diagnosis, our family began to fall apart. Our eldest daughter refused to be in the same room as her dad and barely spoke to him. Our next daughter was in a position to buy a small flat and moved out as she couldn't stand being at home any longer. Our eldest son dropped out of university having panic attacks and the youngest, who was only nine years old, developed Obsessive Compulsive Disorder.

After the diagnosis, I was attending the Psychiatrist with James, Councillors with Lewis and a Child Psychologist with Ross. When we told the children the diagnosis they all reacted differently. Our eldest daughter said I should have left James while I had the chance and the youngest wanted to know if his dad was going to die.

With the diagnosis came my role as carer. Not something that I



James and Maureen McKillop at ADI's International Conference in the Dominican Republic in 2003

'I was married to this man in sickness and in health, so I stuck it out'

was asked if I wanted to do, but something that was assumed I would. This was not an easy task considering that by this time I had come to hate James.

However, I was married to this man in sickness and in health, so I stuck it out.

James thought that now we knew what was wrong with him we could go back to the way things were, but you cannot flick a switch and make all of the hurt disappear. That has to be worked at. Things will never be the same again, and we have accepted that. It took me a long time to learn to take a deep breath and count to a hundred.

Something I was told at my support group with Alzheimer Scotland was

that carers are only human and it is all right to get angry or frustrated at times.

Gradually the children came round and now get on really well with their dad, and are surprisingly understanding.

James has a different quality of life now. He is always busy at meetings to do with dementia. He feels that it is his duty to speak for others who maybe don't have the confidence to do it for themselves.

I feel that I have become a stronger more tolerant person having lived with a person with dementia for so many years.

Read James McKillop's story (Maureen's husband) on page 10.

Members' forum

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

AUSTRALIA

Dementia Preventative Health Strategy

Alzheimer's Australia has released a discussion paper *Towards a National Dementia Preventative Health Strategy*, which reviews factors associated with dementia risk and proposes strategies that could potentially reduce the numbers of cases of dementia. The paper suggests that prevention of dementia is being given insufficient attention considering the prevalence and costs of dementia.

Although it is often considered a normal part of aging, dementia is a chronic disease and therefore it is sensible to take a preventative approach to it. The paper suggests that dementia needs to be addressed as part of a broader preventative health initiative. There are a number of risk factors for dementia that are also risk factors for other major health problems such as heart disease, type II diabetes, stroke, and chronic kidney disease. These include diet, weight, physical inactivity, blood pressure, cholesterol, blood sugar, smoking, and alcohol consumption. Research indicates that by reducing a single risk factor, such as physical inactivity, the number of cases of dementia could be reduced by almost 6% by 2050.

The paper also calls for action to be taken now to address the challenge that dementia poses for the future. It calls for an increase in funding for dementia research and funding for the implementation of existing research and evidence-based interventions, such as Australia's Mind your Mind® programme.

For more information visit www.alzheimers.org.au

BARBADOS

ADI would like to congratulate Pamela Brereton from Barbados Alzheimer's Association, who has been appointed as a member of the country's Mental Health Commission from 2010 to 2012. The appointment was made by Barbados's Minister of Health and we are sure that Pamela will play an important role in this Commission.



Pamela Brereton, left, at the Alzheimer University in Chicago in June

BELGIUM

Alzheimer Café Day

On 10 October, the Ligue Nationale Alzheimer Liga held its fifth Alzheimer Café Day in Brussels. The Alzheimer Café Day is a national event aimed at raising awareness of dementia in informal and welcoming surroundings.

The event consists of continuous activities throughout the day. This year, participants had the opportunity to try *Gymsana*, physical activity sessions designed for the elderly with the aim of improving or preserving their quality of life.

Other activities included a memory game, free sketches by a young artist for visitors and a 'wish tree'. In the evening, participants could enjoy a free showing of the film *Pandora's*

Box in the presence of French actress Tsilla Chelton. The film takes place in Turkey and tells the story of an old lady with Alzheimer's disease and explores the way members of her family deal with the situation.

For more information visit www.alzheimer.be

CARIBBEAN

Regional development

ADI's membership in the Caribbean region has been increasing in recent years and there is a real desire within the region to develop and stand alone as a single region within ADI.

Thanks to the hard work of some particularly strong advocates within our Caribbean membership, awareness continues to be raised with more individuals and groups being encouraged to develop an association where none currently exist.

In August, Norma Inniss from the Alzheimer's Association of Trinidad and Tobago attended the Caribbean Association of Pharmacists meeting, held in St Lucia. Norma was given the opportunity to speak to delegates from 20 countries in the region about dementia and offered ADI materials to all in attendance. 'They all appear to be very interested,' said Norma, following the event, 'I promised to send them World Alzheimer's Day information so that they could have a programme in their country.'

We would like to congratulate Norma on her hard work within the region, and also Melva Croes-Yanez from Fundacion Alzheimer Aruba, who is also working to develop the region.

IRELAND

Economic Perspective report

On 11 October, the Alzheimer Society of Ireland released *An Economic Perspective of Dementia Care in Ireland: Maximising Benefits and Maintaining Cost Efficiency*, a new report highlighting the urgent need for improvements in support through community services for people with dementia and their carers.

In the lead up to the release of the country's Budget 2011 in early December, the Society launched its pre-budget submission stating that, should funding cuts be made to support services, some of the country's 44,000 people with dementia and 50,000 carers would be left without any basic community support.

The report, which was developed in collaboration with Health Economist Dominic Trepel from the University of Limerick, also draws attention to the fact that, in the last year, waiting lists for dementia services in the country have risen by 33% as a result of the increasing impact dementia is having on carers. It was found in a recent survey that two in three family carers in Ireland are caring alone for more than 12 hours a day, three in four carers felt stressed and overwhelmed on a regular basis and 45% had given up work, or significantly reduced their hours, to care for their loved one.

Maurice O'Connell, CEO of the Alzheimer Society of Ireland said: 'We must act now to plan for the future. I firmly believe that the argument for our pre-budget demands for 2011 is not just



Alzheimer Nederland's *Steun de strijd tegen Alzheimer* campaign

a moral one but importantly an economic one too.' The Society is lobbying for dementia to be categorised as a chronic illness and recognised as a national health priority.

For more information visit www.alzheimer.ie

THE NETHERLANDS

In September, Alzheimer Nederland launched a new campaign, *Steun de strijd tegen Alzheimer* (Support the fight against Alzheimer's) to raise awareness of the current issues surrounding dementia care.

The campaign, which hopes to encourage members of the public to donate to the association, highlights that it is currently estimated that one in five people in the Netherlands will develop dementia in their lifetime and, as a result of this, the number of people with dementia is set to double in the coming decades. It explains how unprepared the country is to handle the rise in

people with dementia and the impact it is having and will have on carers. The campaign also draws attention to the cost of dementia in the country and the impending rise of this cost.

For more information about the campaign visit www.alzheimer-nederland.nl/campagne

SINGAPORE

Alzheimer's Disease Association (ADA) in Singapore has been awarded the inaugural Outstanding Voluntary Welfare Organisation Award (Collaboration) by the country's National Council of Social Services. The award was presented for 'working tirelessly with other organisations to raise awareness of their cause'. The National Council of Social Services is the coordinating body for Voluntary Welfare Organisations in Singapore.

To find out more about ADA's work visit www.alzheimers.org.sg

ADI releases landmark report

continued from front page

ADI's website received over seven times as many visitors on 21 September than on an average day. A message from ADI's Chairman, Daisy Acosta, was made available to support member associations worldwide in their own World Alzheimer's Day and World Alzheimer Report launch events.

The launch of the report was marked by events in London, UK and New Delhi, India. Researchers and representatives from other international organisations attended the London event, held at the Institute of Psychiatry, at which Prof Prince and Prof Wimo presented the findings of the report. The event in New Delhi, which took place at the same time as the London event, was attended by around 300 people and followed the launch of the Alzheimer's and Related Disorders Society of India's Dementia India report. Their report details the current scale and cost of dementia in the country.

ADI would like to thank all who helped in the development and promotion of the report and its launch. The report has marked a real turning point for the global dementia movement and we look forward to continuing to build upon it in the future.

To read the *World Alzheimer Report* please visit www.alz.co.uk/worldreport

World Alzheimer's Day 2010 It's time for action!

It was time for action around the world on World Alzheimer's Day 2010 with Alzheimer associations working tirelessly to encourage members of the public and key decision makers to take action to improve the lives of people with dementia and their carers.



Asociacion Dominicana de Alzheimer's street awareness campaign gained media interest in the Dominican Republic

Since 1994, ADI's member associations and other individuals and organisations across the globe have organised and taken part in a variety of events on 21 September to raise awareness of dementia and advocate for better services in care and support.

This year was no exception with Alzheimer associations again demonstrating their ability to develop new and refreshing awareness-raising activities that command attention and call for change.

Memory Walk™, spearheaded by the Alzheimer's Association in the USA, has become a key feature of World Alzheimer's Day in many countries. This year, Zimbabwe Alzheimer's and Related Disorders Association facilitated their walk in conjunction with Island Hospice and welcomed participants of all ages.

The benefits of the arts for people with dementia were considered

during the Romanian Alzheimer Society's World Alzheimer's Day plans, which included a concert featuring the Philharmonic orchestra performing pieces from Vivaldi and Mozart to an audience of people with dementia and carers. The Lanka Alzheimer's Foundation also hosted a sell-out concert, featuring performances by a person with dementia and carers.

Alzheimer associations worldwide recognise the benefits to be gained by releasing a new publication on World Alzheimer's Day. Alzheimer's Australia used their Dementia Awareness Week to host a national launch of three new publications, *Worried About Your Memory* for consumers, *No time like the present: the importance of a timely dementia diagnosis for general practitioners*, and the *World Alzheimer Report 2010*. The Alzheimer's and Related Disorders Society of India hosted a National Dementia Summit to launch

its report, *Dementia India*, calling for the Indian government to improve services for people with dementia and carers across the country. Alzheimer's Disease Association in Singapore used the day to launch a new educational video, *Journey with Grandpa*, which was produced by young people and aims to help children and adolescents understand dementia better.

Alzheimer's Disease Association of the Philippines marked the day by formally opening the offices of their Laguna chapter and Alzheimer Tunisia hosted the launch of their new Alzheimer's centre.

Media coverage is a major part of any Alzheimer association campaign and allows knowledge of services to reach a wider audience. A huge amount of media coverage was received, both locally and nationally. The Greek Association of Alzheimer's Disease and Related Disorders and Alzheimer's Australia received the added benefit this year of having their own television promotion on World Alzheimer's Day. The association in Greece were given a television and radio spot on local and national stations and Alzheimer's Australia, for the first time, had a national advertisement aired. The purpose of the advert, entitled *There's a difference*, was to inform people of the differences in memory problems they should look out for and direct those with concerns to the association's National Dementia Helpline.

The emphasis in a number of countries on World Alzheimer's Day this year was on recognising those who have shown a commitment to improving the lives of people with dementia. In Switzerland, eighteen of Association Alzheimer Suisse's twenty-one local chapters organised award ceremonies to distribute Focus prizes, which were presented to individuals or groups who had made a difference to the lives of people with dementia in their communities. In China, Alzheimer's

Disease Chinese presented Excellence in Home Caring of the Elderly awards to eight family carers from different regions of the country. The association's chapters nominated each award-winner and the event assisted in raising awareness of the necessity for improved dementia care services.

Advocating for better service provision is at the heart of many association's activities and this year saw some encouraging developments. Iran Alzheimer Association received news from the Ministry of Education that they had been granted permission to distribute brochures about dementia to families in the country, starting in Tehran. The government has also asked the association to train health care practitioners. Deutsche Alzheimer Gesellschaft in Germany took part in a press conference run by the country's Ministry of Senior Citizens on 20 September and, the following day, played an active part in the Ministry of Health's conference.

As a result of their awareness-raising activities, Alzheimer associations often receive a higher level of contact from members of the public via their website, email or helpline. Asociación Hondureña de Alzheimer in Honduras received a large volume of telephone calls and feedback from individuals who had heard of the association's work through television programmes and coverage in the press. On World Alzheimer's Day, Alzheimer's Association Japan widely distributed leaflets with an attached questionnaire during their activities. The association received an impressive response to the survey with a total of 3,565 responses received by early November.

With many activities around the world taking place in the weeks or months surrounding World Alzheimer's Day, ADI are still receiving feedback from members on their activities this year. We would



In Switzerland, the signatures supporting the Dementia Manifesto were presented



Ligue Nationale Alzheimer Liga's wish tree on World Alzheimer's Day in Belgium



Alzheimer's Association Japan branches held gatherings and lecture meetings to mark World Alzheimer's Day



A 5km walk through the streets of Alberton was organised in Gauteng, South Africa, with volunteers distributing information about dementia to the public

like to congratulate our members on their increasingly successful events and recognise the determination and tireless efforts they continue to put into making World Alzheimer's Day a success on a local, national and international level. We would also like to thank MetLife Foundation for their generous support of World Alzheimer's Day 2010.

Alzheimer University

London, UK



Participants at the Alzheimer University discuss the benefits of support groups

A small, but active group gathered in London in August for ADI's annual Alzheimer University programme for emerging associations.

Participants from Indonesia, Nicaragua, Russia and Sint Maarten discussed issues such as how to successfully recruit and retain volunteers, fundraising and governance and the role of an association's board.

Hannah Clack, Senior Press Officer for the UK's Alzheimer's Society, ran a lively session on raising profile and awareness and working with the media. The session offered advice on topics including how to write an effective press release and the

importance of developing a strong communications plan.

A new session on building partnerships was presented by Caroline Staffell from the International Alliance of Patients' Organizations (IAPO) and participants considered how collaborations could assist them in developing their work and association.

Participants were asked to consider the benefits of support groups for both people with dementia and their carers. The session, which was run by Jennifer Douglas, a Development Worker for the Scottish Dementia Working Group, also included two open and thought-provoking talks from James McKillop, who has dementia, and his wife Maureen (see pages 3 and 10 for their stories).

The event was a great success and the participants left the course feeling empowered and ready to start work on fulfilling the objectives they set themselves at the end of the programme. Maria Gantman from Russia commented, 'During all the workshops I realised very important things. They were like pieces of a puzzle, and I can't select one as the most beneficial. Nothing can be excluded from the course.'



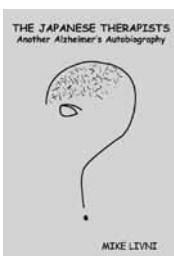
Participants at the Alzheimer University in Seville

Seville, Spain

Participants from nine Alzheimer associations in Spanish-speaking countries joined for an Alzheimer University programme on strengthening their association in Seville ahead of the Alzheimer Iberoamerica conference in October.

The one-day programme, which covered topics including how to set up a helpline or website and communication in the 21st century, was led by Xema Gil, Director of 'Let me think for you', consultants and trainers for the charity sector. Participants were also asked to consider how an association should be governed and what the role of the board should be as well as how to work effectively with volunteers.

The programme was well-received and those in attendance will now begin working towards achieving the objectives they set themselves. A similar programme took place in the Asia Pacific region in 2009 and it has proven to be a popular way of learning more about how to run an Alzheimer association effectively.



REVIEW
The Japanese Therapists: Another Alzheimer's Autobiography
 by Mike Livni

Reviewed by Robyn Yale, LCSW, clinical social worker and author of *Developing Support Groups for Individuals with Early-Stage Alzheimer's Disease: Planning, Implementation, and Evaluation*.

Mike Livni has worked in dementia care for 22 years, serving on the board of Alzheimer's and Related Disorders Association (ARDA) in South Africa as well as ADI. In the early 1990s he became aware of my own work with early stage support groups and was instrumental in bringing it to the ADI forum. While helping to advocate and raise awareness he also began to facilitate early stage groups for people with dementia and their families in South Africa. Now he has arrived at the pinnacle of a 10-year effort to accurately diagnose his own symptoms of dementia, and would like

his first-hand experience to be heard by others.

The Japanese Therapists is a masterful weaving of Mike's personal and professional backgrounds; the writing process with the impact of the disease; and the quest for a diagnosis with the journey to accept it. Because he wants us to understand what Alzheimer's is like for him, he chose not to perfect the text in terms of editing and flow – so we witness in raw and authentic form how his thinking is affected by slowly progressing cognitive impairment. What may at first seem scattered

Regional conferences

ALZHEIMER EUROPE

From 30 September to 2 October, the 20th Alzheimer Europe Conference took place in the multicultural and multilingual city of Luxembourg. Under the theme *Facing dementia together*, the conference aimed to explore ways in which new and necessary partnerships and collaborations could be developed to promote a better quality of life for people with dementia and their carers.

The event, which was supported by Luxembourg's Ministry of Health and Ministry of Family and Integration, featured a variety of sessions, including topics such as reducing stigma and social isolation, ethical issues in dementia care and a special address marking 20 years of Alzheimer Europe.

During the Alzheimer Europe business meeting, Heike von Lützu-Hohlbein from Germany was elected as Chairman. Heike has been involved with Deutsche Alzheimer Gesellschaft, ADI's member association in Germany, for the past twenty years. ADI would like to congratulate Heike on her new post and we look forward to working closely with her and all at Alzheimer Europe in the future.

and disorganised, however, quickly becomes quite engaging. One must admire the skill and courage it took to persevere in recording his story while simultaneously facing and integrating his decline. We are with him "in real time" as he painstakingly writes the book while poignantly searching for answers that were unknowable (as symptoms were mild) for quite some time.

Mike's ongoing reflections are posed to the only "therapists" he worked with during this process – Mr Sanyo and Mr Sony – who, being tape recorders, listened without judgment or criticism.

This is a unique and fascinating read that I highly recommend. Although experienced in the field of early stage dementia, I was educated and enriched by Mike's interesting (and at times wildly funny!) anecdotes, clever musings, and honest expression of feelings. After championing early stage work in his own country and internationally, Mike Livni now contributes to our understanding of the early dementia experience and reminds us of the power one can find to cope with it.

To order *The Japanese Therapists* contact livni@corpdiad.co.za

ASIA PACIFIC

The regional meeting for ADI's member associations in the Asia Pacific region, joined by some of those in the Middle East, took place on 21 to 24 October in Kuala Lumpur, Malaysia. The associated conference was organised by the Alzheimer's Disease Foundation Malaysia (ADFM) and supported by the country's Ministry of Health. The conference programme offered an interesting blend of care and treatment-related topics.

A half-day workshop with a focus on fundraising was organised by ADI before the start of the conference and was attended by participants from fourteen countries within the Asia Pacific and Middle East regions. Mayan Quebral from Venture Fundraising in The Philippines spoke to the group about the best practices in fundraising and ADI's Executive Director, Marc Wortmann, led a session on the principles of fundraising. Participants at the workshop were later invited to visit one of the ADFM's day care centres before the regional business meeting that afternoon.

The conference, meeting and workshop made for a very successful



Emilio Marmaneu, centre, at the Latin America regional conference closing ceremony in Seville, Spain

event with much discussion on ways in which to bring the region closer together. ADI would like to thank and congratulate ADFM for their hard work on this event.

LATIN AMERICA

The cultural and artistic city of Seville in Spain played host to the regional meeting and conference of Alzheimer Iberoamerica, the group made up of associations from Spanish-speaking countries in the Americas, as well as Brazil and Spain. The conference, which took place from 21 to 23 October under the theme *Juntos podemos* ('Together we can'). It was combined with the Fourth National Congress of Alzheimer's, an event run by Confederación Española de Familiares de Enfermos de Alzheimer y otras Demencias (CEAFA), ADI's member association in Spain, in collaboration with Sociedad Española de Neurología and Sociedad Española de Geriátría y Gerontología.

The conference programme included clinical and psychosocial sections, and practical workshops. A separate exhibition space was set aside to house drawings by carers of all ages accompanied by soft music and lighting, making for a very moving and thought-provoking experience.

Emilio Marmaneu, President of CEAFA, was presented with an award at the conference closing ceremony for his work on defending the rights of people with dementia.

■ Living with dementia

Does dementia affect family relationships?

James McKillop, Scotland

You have already read Maureen's story (page 3) about the gradual deterioration in spouse, children and social relationships, stretching back over a number of years, which caused very deep wounds on either side. Though the scabs have healed, the scars still remain deep inside, but on the surface, the signs are growing fainter.

But will they ever heal completely – only time will tell.

My unreasonable, bizarre behaviour and my false accusations caused a complete breakdown in communication with my wife and children and led to my being ostracised within the household. We were weeks away from my wife walking out and divorcing me, as there was no indication that I had an illness causing the inexplicable changes in me.

We are still together, thankfully, but there is a change of role in the marriage, a complete reversal in fact.

Maureen is now the man in the house, going out at 7am daily to be the breadwinner, while I lie snoozing in bed. It can be shameful for a man, especially when she goes out in winter.

She now makes all the financial decisions: what can we afford to buy, where we can afford to go on holiday, when the car needs replacing, balancing the bank statements and ensuring we stay within budget etc. I struggle to manage the complexities of a few pounds pocket money.

She deals with home and family matters, while I am indecisive and just can't make up my mind on anything, then forget what I have decided when I do finally come to a decision. Then I have to go over the problem again and may come to a different decision. I contradict myself constantly.

I no longer answer the door when she is in. I ignore the door when she is out. Likewise, I avoid the phone if she is out.

She has the responsibility of the security of the house, while I have been guilty of gaily swanning out, leaving doors and windows unlocked, yet no one was in the house. It is a godsend we weren't burgled.

She took my place at school parents' evenings while I skulked at home, in case I inadvertently said something inappropriate, or took umbrage at a supposed slight.

I travel by myself within a comfort zone and need a supporter if I go outside it. I no longer drive so she takes me places. She copes with the hazards of driving while I sit back, admire the scenery and comment on her driving.

While she thought she had finished bringing up a family, she now has to cope with an adult whose behaviour can be childish and naïve at times. I am the child she didn't give birth to.

She has to endure endless repetition of the same questions or the same comments, day after day. This can be very wearying and lead to carer's fatigue.

She has to shadow me to protect me from myself, and double check everything I do. She doesn't trust my judgement any more and it is hard to see how she can hold me in the same regard or treat me with the same respect as she once did.

Have I become a burden or a liability to her?

When dementia walked in the door, did romance fly out of the window?

How does she cope when things become too much for her and she can't turn to me for comfort and advice? She does discuss matters with me but take heed, I think not. She



James and Maureen McKillop

didn't apply for the job of a carer; she was headhunted.

The answer is that she is one in a million and takes everything in her stride. She has grown broad shoulders, picked up the gauntlet and has taken over the role of what is now, in effect, a one-parent family.

You could say my quality of life is very good. I have no responsibility and get looked after. However, I do feel quite institutionalised, as I have come to depend on her so much. For example, if I come across a problem I go running, childlike, to her to report it and let her deal with it. Previously I would have dealt with it myself and never dreamt of delegating. She now runs the house and the family.

However, before you think that life is all doom and gloom, can I point out that I have been writing about one facet of my life, which has not gone too well?

There are other sides to my life where I am doing well and encouraging other people with dementia to make the most of their lives. These are separate stories, and for another time. Briefly though, I brought out a Helpcard and was co-author of a booklet to be given out at the point of diagnosis. I also brought out a book of photographs and have contributed to newspaper and magazine articles.

■ Research update

Non-pharmacological therapies

Bob Woods

Dementia Services Development Centre Wales, on behalf of the International Non-Pharmacological Therapies Project

Medication is usually the focus when new treatments for Alzheimer's and other dementias are being discussed. Recently, the question of the value of other forms of treatment for people with dementia has been scientifically addressed, and the evidence for their effects can now begin to be evaluated.

Non-pharmacological therapies (or NPTs) are wide ranging in approach. They include approaches as diverse as cognitive training, the therapeutic use of music, physical exercise, massage, reminiscence therapy, education for carers, support groups and psychotherapy. They encompass psychological, psychosocial, interpersonal, behavioural, emotional, exercise and environmental interventions. Their development bears witness to the creativity and commitment of many professional and lay carers of persons with dementia around the world.

The goals may be short-term or immediate; for example, a hand massage or a music session may aim to calm the person with dementia for the duration of the session, without necessarily having any noticeable effect one hour later. For someone who is rarely calm, this may be a valuable achievement. Of course, if there is an approach that has more lasting effects, that might be preferred.

The evidence from research studies on NPTs has been reviewed by groups in several countries, and by international collaborative groups, including the International Non-Pharmacological Therapies Project. This project screened over 1300 research papers, classifying NPTs in 26 different categories. The research is of variable quality

and many gaps exist. High quality studies are scarce (due mainly to inadequate funding) and evidence on the effectiveness of some well-established approaches is not available.

However, there are promising indications of the effectiveness of some interventions. These include:

- Certain interventions with family carers, involving an individualised package, combining several approaches based on a comprehensive assessment of the carer, the patient, the family and the social environment. Components of this intervention may include training and education, use of resources (for example, day care, support groups, respite services) and organising additional family support. There is strong evidence that this inexpensive, flexible intervention improves psychological well-being of the carer, and prevents or delays costly care home placement.
- A combination of therapies for the person with dementia, including cognitive stimulation, physical exercise and other components in different proportions, has been demonstrated to improve daily functioning, cognitive capacity and mood (reducing depression), whilst also reducing behavioural symptoms that can severely distress carers.
- Behavioural interventions to reduce disturbed behaviour, involving individual work with family carers or training for care-workers have been shown to be effective in a number of studies.

These approaches have all been evaluated in randomised controlled trials, with the effects assessed by raters not involved in the delivery of the therapy. They are listed to indicate the range of approaches which already have evidence established for their effectiveness. Inevitably, there is more evidence available on approaches that can

be packaged and delivered in a standard and consistent manner. Approaches aiming to change the care environment or requiring a great deal of individualisation of the treatment approach are more difficult to evaluate rigorously.

Some NPTs do require specialist training, such as cognitive-behaviour therapy for depression in carers, but in most cases, care-workers without formal qualifications who receive specific training are able to implement the approach as part of a day to day routine. Training packs and manuals are available for a number of approaches. The prerequisite is that all those involved in implementation have good person-centred care skills. The underlying principles and values of person-centred care are embodied in the following statement:

'A person with dementia is a person of worth and dignity, deserving the same respect as any other human being'
(ADI Charter of Principles, 2003)

In practice, the first step is to identify, with the person and their supporters, the areas important to focus on – those where a small change could bring about a significant improvement in quality of life. These individual goals can then guide the choice of NPT, bearing in mind the individual pattern and profile of wishes, past and present likes and dislikes, abilities and impairments. For the future, further research needs to proceed alongside implementation of current findings. Alzheimer associations have a key role in encouraging both innovative practice and the development of research into NPTs. They should seek effective ways to achieve the implementation of NPTs, for the benefit of people with dementia and their carers.

The published paper from the International Non-Pharmacological Therapies Project and supporting materials are available at www.NPTherapies.org

■ Obituaries

Here in the ADI office we were sad to learn of the recent passing of two very important members of the global dementia community.

Tom Ennis

Tom Ennis was at the forefront of ADI's work from the very beginning, most notably as Secretary General from 1984 to 1986 while also serving as executive director of the Alzheimer's Association in the USA. His commitment to improving the lives of people with dementia was inspirational and continued for many years, most recently with The John Douglas French Alzheimer's Foundation. We extend our condolences to Tom's wife Julia and son Tom.



Keith Turner and his wife Lillian (far right) with representatives from Jamaica and Tunisia at the Alzheimer University in 2007

Keith Turner

Keith Turner, who was diagnosed with early onset Alzheimer's disease in 2004, passed away in October following a long period of illness. Keith was a great advocate for people with dementia, particularly in the UK where he was an ambassador for Alzheimer's Society, and fought hard to ensure people with dementia received the

treatment they needed. Along with his wife, Lillian, Keith became a memorable part of ADI's Alzheimer University programme for emerging associations in 2007 and 2008, and visited Alzheimer's Jamaica on World Alzheimer's Day 2007 to help with their awareness-raising campaign. Keith will be greatly missed by many and we send our deepest sympathies to Lillian.

The 7 Summits Climb for Alzheimer's

Alan Arnette, a 54-year-old mountain climber and dementia advocate, is scaling seven of the world's highest summits to raise awareness and funds for dementia research.

Alan, whose mother had Alzheimer's disease and passed away in 2009, began his year-long expedition on 24 November by starting his climb of the 4897-metre Vinson Massif in Antarctica.

'The mental and physical demands of scaling seemingly insurmountable peaks are not unlike the everyday challenges faced by those living with Alzheimer's disease and their caregivers,' said Alan, who retired from his job with a leading technology company to care for his mother after her diagnosis. 'Both involve understanding personal limitations, reaching out for support and taking steps daily on a very long road.'

Alan's challenge will see him scale the heights of Aconcagua in Argentina, Everest in Nepal, Denali in Alaska, Elbrus in Russia, Kilimanjaro in Tanzania, and Carstensz Pyramid in Indonesia. He also hopes to make time to reach the top of Mount Kosciuszko in Australia by the time his challenge ends in December 2011.

Alan's climb has been made possible through funding from the Alzheimer's Immunotherapy Program of Janssen Alzheimer Immunotherapy and Pfizer.

You can follow Alan's progress at Climb4AD.com

Place your vote for Alzheimer symbol

In June, a request was sent out for a new symbol to represent dementia worldwide and the global dementia movement. Eighty-six entries were received from fourteen countries and these were then sent to the specially appointed judging panel for consideration. Judges for the competition included Christine Bryden, a person with dementia living in Australia, John Murphy, a branding specialist based in the UK, and Amit Dias, an epidemiologist and geriatrician in Goa, India.

The judges' task was to select the top five entries received and these entries will shortly be made available on ADI's website for voting. The symbol we are looking for needs to represent the global movement made up of national Alzheimer associations around the world, whilst taking into consideration the caring and supportive nature of our work.

The five entries will be available for voting shortly, so please do take a few moments to have your say on this very important international symbol. Voting will close in February 2011.

To find out more visit www.alz.co.uk/symbol