



Global Perspective

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

Policy Watch

Members rally to effect change



Minister of Health in Chinese Taipei, Sheng-Mou Hou, is presented with the Asia Pacific Report and signs the *No Time To Lose* banner



Glenn Rees, Executive Director of Alzheimer's Australia, and Lynne Pezzullo, Director of Health Economics from Access Economics, at the official launch of the Asia Pacific Report

In the past, most Alzheimer associations have focused primarily on the important role of providing help and support to people with dementia and their families. As associations develop, more and more are realising their potential to effect change and seizing opportunities to advocate to improve public policy.

Over the last few months we have seen many associations

emerge as powerful voices in the political arena. In the December edition of *Global Perspective*, ADI reported on the World Alzheimer's Day launch of the Asia Pacific report *Dementia in the Asia Pacific Region: The Epidemic Is Here*. A few months later we have had a chance to reflect on the impact of the report.

Alzheimer Europe has also been investing in advocacy. At

the Annual Meeting of Alzheimer Europe in Paris in June 2006 the Paris Declaration was unanimously adopted. This document outlines the political priorities of the European Alzheimer movement and is a veritable call for European policy makers to make dementia a public health priority. Here we report on the details and initial impact of these documents.

The Dementia Epidemic in the Asia Pacific Region

The report, *Dementia in the Asia Pacific Region: The Epidemic Is Here*, warns that dementia has the potential to have a devastating impact on the health systems of Asia Pacific countries and the quality of life of their people.

The report recommends that all Asia Pacific governments should

create the climate for change through greater awareness and destigmatisation of dementia. They are encouraged to build effective constituencies and coalitions for partnership between policy makers, clinicians, researchers, carers and people with dementia. They are also encouraged promote the

development of responsive and effective care services.

The report was produced to encourage regional advocacy and to help member associations with their advocacy efforts. Countries in the region were encouraged to take the report to their health ministries, other health organisations and to the media.

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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 **1 June 2007**.

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■ Editorial



Marc Wortmann
Executive Director

Going through the final preparations for the plenary programme of this year's ADI conference (10-13 October in Caracas, Venezuela), I have paid extra attention to recent updates and advances in research. ADI's 10/66 Dementia Research Group always provides us with interesting information. In February a report on the figures and costs of dementia within the UK was launched by the Alzheimer's Society, and the World Health Organization launched Neurological Disorders: Public health challenges. These, along with the report from the Asia Pacific region launched on World Alzheimer's Day last year, provide powerful information for use in both raising awareness and influencing public policy.

We have also read that new drugs are on their way, that a second gene, SORL1, is found to have a connection to the disease and that even cats can have Alzheimer's disease. Lots of articles are written on the connection between nutrition and dementia and although many are unsupported by 'hard' evidence we should take heed and invest in further exploration of the topic.

Many of our member associations raise money to encourage research with which to advocate to governments. The money spent on research is not sufficient in proportion to the enormous problem we face with the approaching dementia epidemic. However, if we show the positive effects of the medical and social research conducted so far we might well be able to successfully apply for more funding. That is why our 2007 conference is on the theme: New Perspectives, New Hope. I invite all our readers to Latin America and to be part of it. You can find more information on the conference website at www.adi2007.org. I look forward to seeing you there!

■ Events

3 – 4 April 2007

1st International Conference at Stirling

Citizenship: Responding to the Challenge of Dementia
Stirling, UK
Fax: +44 20 7498 3023
Email: shital@hawkerpublications.com
Web: www.dementia.stir.ac.uk/events/international/conference_main.htm

10 – 13 April 2007

Brain Ageing and Dementia in Developing Countries Symposium

Nairobi, Kenya
Tel: +44 191 256 3206
Fax: +44 191 256 3011
Email: advvascular@ncl.ac.uk
Web: advvascular.ncl.ac.uk

27 – 28 April 2007

Alzheimer's New Zealand National Conference

Dementia Across the Ages
Wellington, New Zealand
Tel: +64 4 381 2361
Fax: +64 4 381 2365
Email: nationaloffice@alzheimers.org.nz
Web: www.alzheimers.org.nz/conference.php

9 – 12 May 2007

17th Alzheimer's Europe Conference

The Sound of Silence
Estoril, Portugal
Tel: +351 21 361 04 60
Fax: +351 21 361 04 69
Email: alzheimers@netcabo.pt
Web: www.alzheimer-conference.org

29 May – 1 June 2007

Alzheimer's Australia 2007 National Conference

A Journey of Passion and Purpose. The next 100 years
Perth, Australia
Tel: +61 89 389 1488
Fax: +61 89 389 1499
Email: info@eventedge.com.au
Web: www.alzheimers2007conference.com.au

9 – 12 June 2007

2nd Alzheimer's Association Prevention Conference

Washington, USA
Tel: +1 312 335 5790
Email: prevention@alz.org
Web: www.alz.org/preventionconference

26 – 29 August 2007

15th Annual Alzheimer's Association Dementia Care Conference

Chicago, USA
Tel: +1 312 335 5790
Fax: +1 866 699 1246
Email: careconference@alz.org
Web: www.alz.org/careconference/07

10 – 13 October 2007

23rd International Conference of Alzheimer's Disease International

New Perspectives New Hope
Caracas, Venezuela
Tel: +58 212 263 9733
Fax: +58 212 263 3672
Email: info@congrax.com.ve
Web: www.adi2007.org

8 – 11 November 2007

5th International Congress on Vascular Dementia

Budapest, Hungary
Tel: +41 22 90 80 488
Fax: +41 22 73 22 850
Email: neuro13@post.tau.ac.il
Web: www.kenes.com/vascular



Thank goodness for Bing!

By Ann Saunders, UK

The hardest decision of my life was booking a place at a local residential home for my mother who has dementia. Although I didn't feel guilty – I knew I was doing it for the very best reasons – I cried into my pillow the night before the morning on which I rang the home's manager.

My mother, Bettie Priestley, 89 this month, moved to the home in July 2005. Her main problem is lack of short-term memory. She has retained her sense of humour and still recognises me and can even recite the names of my four siblings.

When she moved into the home, I told the manager about my mother's life and what her interests had been before she developed dementia. This really helps the staff know something about the resident and helps them to see the person behind the illness. In my mother's case, she was a marvellous homemaker, a brilliant seamstress, well-travelled, and always smartly-dressed. The carers were quick to flatter my mother on her hair or dress, which went down very well and certainly helped her settle into her new surroundings! I have also put up an enlarged picture of my mother in her 30s caressing my younger sister as a baby. The picture asks the staff to remember that Bettie had a full and fulfilling life before dementia.

I really admire the staff at my mother's home. In her New Year's letter, the manager wrote, 'We genuinely care about what we're doing. Our job isn't always easy and certain elements of the media would have you believe that cruel, insensitive people staff many care homes. We are aware of our imperfections and we know that we're none of those things, but are fairly useless at getting the laundry right at times!' I now realise that, although seeing my mother in someone else's clothes from time to time is upsetting, does it really matter? As long as she seems content and well-turned out, I continue to know the carers are doing an excellent job.

Whereas my mother's physical abilities are not as good due to her more inactive lifestyle, she has not



Bettie Priestley - and, inset, with her daughter Ann

deteriorated mentally as much as I thought she would. I put this down mainly to visiting my mother regularly with weekly trips to my house for lunch and of course, various activities laid on by the home. I find it very calming for my mother, and funnily enough for me, to spend time looking at old photo albums or manicuring her nails, giving her a facial and listening to music. She has become devoted to the music of Bing Crosby, whose CDs I started buying a year ago. The carers now say Bing is instrumental in getting her out of bed in the morning or in distracting her if she is being a bit aggressive. She sings along with Bing remembering most of the words.

Since my mother went into the home, I find I am now a lot more patient and calm with my mother. I now can give her quality time whereas before I was snappy, tired and irritable. Our roles have reversed and she is now like a child who has to be directed and distracted. Thank goodness for Bing! I have told my children to play The Beatles for me, if ever the time comes.

ADI announces twinning projects for 2007

ADI is happy to announce that this year's Twinning Programme partnerships are Bulgaria and Israel, India and the Alzheimer's Society (England, Wales, Northern Ireland), and Mexico and the Los Angeles chapter of the Alzheimer's

Association (USA). In the next few months we shall be helping the associations arrange their first site visits and assisting with preliminary communications to help each association get the best out of the programme. As the twins embark

on their site visit they will get to know each other better and gain an understanding of the reality that the other association operates within. This will also be the time where they will set their objectives and work plan for the next three years.

Members' forum

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

Hungary

Musical prayers given in memory of Ferenc Puskás

Ferenc Puskás, legendary Hungarian football forward and coach, is considered one of the best footballers ever. He was one of the most effective goal scorers of all time before retiring from the sport and being diagnosed with Alzheimer's disease in 2000. He was admitted to a Budapest hospital in September 2006 and died on November 17, 2006 of pneumonia.

In December a musical concert was held in Budapest in his memory and to commemorate the end of the centenary year of Alzheimer's disease. The concert was jointly organized by the Hungarian Alzheimer Society and Zoltán Mága, the famous violinist, and took place at the spectacular Matthias Church in the heart of Budapest.

Voted as the greatest sportsman of the 20th century, Puskás was honorary ambassador for Hungarian sports, his name adorning the largest football stadium in the country. This magical musical event provided an opportunity for remembrance and reflection for one man with a great legacy but also for the millions of others living with dementia who inspire our work and remain always in our prayers.



A musical tribute to people with dementia at the Matthias Church, Budapest



Most cases of dementia are not inherited

PHOTO BY NICK KONTOU

Scotland

The genetic factors of dementia

Alzheimer Scotland has launched a new publication explaining the present knowledge about inherited risks of dementia. The leaflet is aimed at people who have a diagnosis of dementia, and their close relatives who may be concerned about inheriting the illness.

Kate Fearnley, Policy Director for Alzheimer Scotland says, 'A lot of people worry about dementia getting passed on down the family. In fact, most cases of the illness are not inherited. The illness is so common that even having two close relatives is not evidence of a family link, although there are some rare forms of dementia which are caused by genetic faults. With most cases of dementia, your genetic make up may affect your risk of developing dementia in later life, but so do lots of other things, such as your environment and lifestyle. Having a close family member with the condition only increases your risk by a small amount.'

The best known genetic risk factor for late onset Alzheimer's disease is a gene called Apolipoprotein (ApoE), which comes in three forms, one of which seems to increase the risk of developing Alzheimer's disease, but does not make it certain. Testing for this gene is not generally useful, as it does not predict whether someone will get the disease, and there is no special treatment for anyone who has the gene.

Anyone who would like to know more about genetics and dementia can go to www.alzscot.org for an information sheet.

UK

New research to reveal state of dementia

Groundbreaking research into the rising cost of dementia in the UK headlines a national dementia conference in London. The London School of Economics and King's College London report, Dementia UK, commissioned by the Alzheimer's Society, will provide new evidence of the human and economic cost of dementia.



Bruce, with his wife Jan. Bruce cared for Jan at their home for ten years before Jan moved to her present specialist nursing home in 2001

The conference, entitled *The rising cost of dementia in the UK – Are we prepared?* will expose the true state of dementia in the UK with key speakers from the London School of Economics and Alzheimer's Society announcing the report findings.

Neil Hunt, Chief Executive of the Alzheimer's Society, says, 'By 2050 the number of people with dementia in the UK will double to 1.8 million. This will place an intolerable strain on our health and social care system unless we act now. This vital research will give more accurate evidence of the impact of dementia in the UK, the cost of dementia to individuals and the state, and projections on the rising cost of care.'

Bruce Bovill, a carer for his wife Jan who has early-onset dementia, says, 'Dementia not only impacts on the person with dementia, but also on carers, families and loved ones of the individual. Dementia UK is essential research which, for the first time, will provide a basis for planning for the increased need for dementia services in Britain.'

As well as releasing the report findings, the conference boasts a line-up of speakers from the NHS and social care, and people with first hand experience of dementia. For more information go to www.alzheimers.org.uk

Iran

Iran Alzheimer Association spreads the word through local provinces

At the end of last year ADI sent a series of letters to the Iranian Interior Ministry encouraging them to support the work of the Iran Alzheimer Association (IAA). IAA followed this up and are very happy to announce that, as a result, the ministry contacted all the Iranian provincial central offices with instructions to include dementia on their local health agendas.



Staff at the Iran Alzheimer Association

IAA were quick to send information kits to all the provincial centres and has already held two successful meetings with the provincial health groups of Semnan and Tehran. Since the meetings, IAA has had follow up letters from the groups asking for more information and help.

Ireland

Ireland announces Dementia Manifesto



Carers, people with dementia and politicians take part in the first consultative meeting in Dail Eireann (House of Parliament)

The Alzheimer Society of Ireland has launched a three year strategy, the Dementia Manifesto 2007-2009, to outline how their government should look after and provide for those with dementia.

Over 38,000 people in Ireland have dementia and a further estimated 50,000 people have had their lives profoundly changed by having to assume the role of carer. According to the society, every day, 11 new cases of dementia arise in the country and, as a result of population ageing, 71,000 people will be affected by 2026.

The Dementia Manifesto calls for an investment of €105 million over a three-year period, which would be spent on key areas including community-based services, early diagnosis, intervention, awareness and education along with social and medical research.

Altogether, the society, which this year celebrates its 25th anniversary, is calling for €63 million to be invested in community-based services.

■ Research update

Effect of solitude on risk of developing dementia

Lonely people may be twice as likely to develop dementia, according to researchers in Chicago, USA.

The effect of social isolation in old age was tested on a total of 823 older people. At the time of enrolment all were healthy and free of dementia. Loneliness was assessed at the outset and annually thereafter.

During the follow-up, 76 subjects developed Alzheimer's disease. Risk of Alzheimer's disease was more than doubled in lonely people compared with people who were not lonely. Loneliness was associated with lower level of cognition initially and with more rapid cognitive decline during follow-up.

In the Archives of General Psychiatry journal, Dr Robert



Researchers are looking into the effect of solitude on the risk of developing dementia

PHOTO BY JURY GREGORIO

Wilson said, 'Humans are very social creatures. We need healthy interactions with others to maintain our health. The results of our study suggest that people who are persistently lonely may be more vulnerable to the deleterious effects of age-related neuropathology.'

Although the researchers also looked at the question the other way round, they found it unlikely that the onset of Alzheimer's caused people to feel lonely.

<http://archpsyc.ama-assn.org/cgi/content/abstract/64/2/234>

Coffee drinking may reduce risk of dementia

A group of healthy older men from Finland, Italy and the Netherlands participated in a 10-year prospective study to determine the effect of coffee on cognitive decline in elderly men.

Men who consumed coffee showed significantly less cognitive decline over a 10-year period than those who did not. An inverse association was observed between the number of cups of coffee consumed and cognitive decline, with the least cognitive decline for three cups of coffee per day. These findings suggest that consuming coffee may reduce cognitive decline in elderly men.

<http://www.nature.com/ejcn/journal/v61/n2/abs/1602495a.html>

■ Living with dementia

Alzheimer's Association Japan launches new initiatives for people with dementia

by Kunio Takami, National Representative, Alzheimer's Association Japan and Issho Matsumoto, Chair, International Exchange Committee

The Alzheimer's Association Japan (AAJ) has established an early-onset dementia committee offering support for people with dementia and their families throughout Japan. On 16-17 October 2006, the Ministry of Health, Labour and Welfare collaborated with AAJ to hold the first ever meeting in Japan for people with dementia when the 'People with Dementia Meeting Appeal' was adopted. This appeal is the first time that people with dementia themselves have spoken about their situation to society

in a structured statement. It is summarised below.

People with dementia meeting appeal

- 1 *We want to create the opportunity for people with dementia to talk amongst themselves.*
- 2 *We want you to understand that we have dementia.*
- 3 *Please listen to our innermost feelings.*
- 4 *We want our preferences to be reflected in policies.*
- 5 *We want you to take the burden off our families.*

People with dementia in the UK join forces

The First UK Planning Group of People with Dementia took place in Birmingham in January 2007. People with dementia came

together from across the UK at this event, organised jointly by the Alzheimer's Society and Alzheimer Scotland.

The aims of the meeting were to plan a national conference and set up a committee to represent the views of people with dementia in the UK. Issues discussed by the group included: experiences of media and policy involvement, respite care, access to insurance and driving. The group's next steps will be organising a future planning meeting, sharing practical tips and raising funds to organise a national conference.

'My wish is to see us being taken seriously and respected for who we are, by the people who have the finances and power to make change happen,' said James McKillop of the Scottish Dementia Working Group.

Policy Watch

Members rally to effect change

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It would have been unrealistic to expect immediate policy changes after the launch of the report. However, the majority of countries and associations involved have reported some shift in perceptions of dementia. Sung Hee Lee of Alzheimer's Association Korea said, 'There are many developing countries in the Asia Pacific region. Even though we have come up against a dementia epidemic, our governments do not recognize this because of our limited economic or cultural circumstances. This report is so important in breaking their silence on dementia.'

Many associations involved local politicians and the media in their launches of the report. The Goa chapter of ARDSI, the association in India, told us, 'The information was disseminated through the media and a copy was sent to officials concerned with the health of the people. Though the situation is still not bright, it is much better than what it was a few years ago when we just started. I thank ADI for this initiative to come up with the much-needed Asia Pacific dementia statement.'

The report is available at www.alz.co.uk/research/asiapacificreport.html.

Making dementia a public health priority in Europe

In the Paris Declaration, Alzheimer Europe issued a call for action to improve the situation of the 5.8 million European citizens living with dementia, as well as that of their informal or family carers. In particular, the declaration called on European and national policy makers to:

- make Alzheimer's disease a public health priority by developing national and European action programmes on Alzheimer's disease and by increasing the funding of research into the causes, prevention and treatment of Alzheimer's disease and other dementias;
- promote the early diagnosis of the disease by developing awareness campaigns on Alzheimer's disease and making dementia a compulsory part of medical training;
- improve the quality of life of people with dementia and their carers through the development of support and respite services and increased financial support for these services;

- promote the autonomy and dignity of people with dementia through systematic information for people diagnosed, the recognition of advance directives and improvements to existing guardianship systems.

The Alzheimer Europe Yearbook *Dementia in Europe*, which was also launched at the meeting, provides comparative data on the numbers of people with dementia, the reimbursement systems and provision of home care in 31 different European countries.

Astrid Lulling, Member of European Parliament, commented: 'As European politicians, we welcome these important contributions by Alzheimer Europe. The Yearbook provides much needed information on the numbers of people affected by Alzheimer's disease and other forms of dementia. We need to make dementia a European public health priority right now.'

Maurice O'Connell, Chairperson of Alzheimer Europe said, 'We are encouraged to see the growing commitment of European and national policy makers to give Alzheimer's disease the priority it so justly deserves. We now expect clear actions on a European and national level.' He called on policy makers and concerned individuals to support the Declaration and call for action of the organisation on its newly launched website:

www.dementia-in-europe.eu

The increased activity of Alzheimer associations in the world of politics and advocacy provides us with exciting opportunities to effect change and have our say in the way people with dementia and their carers are provided for. Forming alliances and producing reports and declarations are effective ways of attracting the attention of policy makers. We look forward to reporting back with more news on the impact our efforts are having on the future for people with dementia.

Life with dementia captured on film

Those who attended The Scottish Dementia Working Group's session at the ADI conference in Berlin may be interested to know that there is a DVD on the group's work available for purchase. The film, *United we stand*, introduces each member of the group and follows their progress as they lobby MSPs outside the Scottish Parliament and campaign for change. The film is available for £7.50 from www.alzscot.org/store/pages/DVD_-_United_We_Stand21115817.htm

The Doncaster-based People Respect Other People (PROP) is a group of people with dementia who have produced a DVD looking at every day issues that they face. Cost: £15 plus postage. Contact: carol.jubb@virgin.net

New care initiative excels in UK care homes

Abdul Patel is a carer working with residents with early onset dementia at the Forrester Court care home in North London. 'It takes a little imagination to see beyond the routines. Looking for new, creative ways to get the residents involved is one of the key challenges of the job,' he says, describing a new project which aims to involve care home staff with the day to day lives of those in their care. 'Every task can be seen as an opportunity. We've realised that many of the residents are far more capable than we thought if the task is broken down into a series of small steps.'

2007 promises to be an interesting year for staff and residents in Care UK homes. Opportunities to stay active are about to increase following a major rethink of staff priorities. Project manager David Clegg discusses the benefits and challenges of the new 'activity based' company philosophy.

David explains, 'We asked residents what would really make a difference to their experience of life in the homes and almost without exception they said that they would like to be able to do more for themselves. Sydney, a resident, put it very well when he said that it was the little things that made the difference rather than more timetabled activities: having a carer spend an extra few minutes to help him make his own cup of tea, being able to butter his own toast, put the food on his plate, making his bed or going to buy a newspaper... He thought he wasn't even allowed to try.'

The aim is to help all the residents maintain as many of their former lifestyle choices as possible and that now includes some activities that tend to be overlooked as unimportant. Staff realised that they had sometimes placed too much emphasis on running home routines by the clock, reducing the opportunities for interaction while carers rushed around completing simple tasks some of the residents might actually enjoy doing themselves.

Staff began by asking what 'care' really means in 2007: what they would want for themselves or their

relatives, and they realised that at times they may be stepping in too quickly. A pilot was run in five homes where staff began to notice real improvements in resident mobility and communication. Many residents proved to be far more capable than previously thought.

Geraldine Sainsbury, a team leader on a unit for elderly people with dementia, explains: 'We realised that a lot of the information on referral forms was wrong. They tended to look at what someone couldn't do rather than what they could. We've learnt not worry too much about what's on a pre-admission form; let's assume they can do everything until we find they can't.'

Inevitably some tasks take a little longer and some days run more smoothly than others but staff note that there has been a reduction in challenging behaviour with the units feeling calmer. In a year not one member of staff has said they would prefer to return to the previous way of working. David explains, 'It's important that all staff at every level realise that keeping residents active is an integral part of basic care.'

Even though it is a very simple philosophy, David stressed that each and every member of staff needed to be in full support of the new initiative. Daily decisions have to be rethought from recruitment and training to making sure the right teapots were ordered and the furniture arranged correctly. 'The environment can work as an extra pair of hands. Something as simple as turning off the television, leaving newspapers or reminiscence cards on the table or ensuring a favourite doll isn't locked away can have huge benefits.'

David concludes, 'Once we began to see outside the routines of physical care there were far more opportunities than we realised. It actually made the job much more fun, it had real benefits to the residents and it didn't take any more work. It's a far more rewarding approach for everyone and ultimately it means a better quality of life for our residents.'

For more information contact David Clegg at david.clegg@careuk.com



Residents are busy in the activity lounge at Kingsleigh Care Home in Woking, UK