



Alzheimer's Disease
International

April 2009
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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.

25 years of Alzheimer's Disease International

ADI was founded on 21 October 1984 in Washington DC, USA. Throughout this year in Global Perspective we will present the highlights of 25 years of the Alzheimer's movement. In the next issue we will look back on the early years in more detail. In this issue we focus on the governance, information provision and research of ADI.

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ADI Supporters programme

ADI has launched a programme for individuals who want to be more connected in the international dementia community. Membership of ADI is restricted to national Alzheimer associations (with certain regional exceptions agreed by our members), but we want to extend the options for making connections and so we have created the ADI Supporters programme.

We have previously offered the opportunity to subscribe to our newsletter, but we never promoted it much. We know from regular requests that researchers, professional carers and other people within our movement would like to hear more from ADI. We are not intending to look for ADI Supporters outside of the existing dementia care community – that remains the role of our member associations.

ADI Supporters will, for an annual fee, receive the Global Perspective and 10/66 newsletters, either by email or by mail, as well as emails highlighting ADI and dementia news and information about conferences and events. Importantly, ADI Supporters will also be contributing financially to ADI's programmes that support Alzheimer associations throughout the world. People can join the Supporters programme at www.alz.co.uk/supporters



Alzheimer's Disease International

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Send us your comments

If you have any comments about or items for the newsletter please contact the Secretariat. Articles for the next issue of Global Perspective to arrive by 31 May 2009.

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■ Editorial



Marc Wortmann
Executive Director

This first issue of Global Perspective in 2009 contains many updates on activities in the global Alzheimer's movement. I am very grateful for all the information that was sent to us by members and potential members. It is good to share our experiences as we can easily learn from and encourage each other to deal with the main issues around this disease. Many of them are similar, whether you live in the North or South, East or West, or in more or less wealthy communities. Alzheimer's and most other dementias are very democratic diseases: everyone can be affected. So, please do keep sending us your news and experiences.

A hot topic in more and more countries is prevention. Our Medical and Scientific Advisory Panel (MSAP) have started an initiative to share ideas around the world, thanks to a proposal from Prof Barry Reisberg who is now responsible for bringing this forward. Several members of ADI have launched campaigns to draw attention to prevention and risk factors of dementia. In this newsletter you will find a research update from our former Chairman, Prof Henry Brodaty, on this important topic. It is also on the agenda of this year's and future ADI conferences.

■ Events

2009

25 – 28 March 2009
24th Annual International Conference of Alzheimer's Disease International
Dementia: Engaging Societies Around the World
Singapore
Tel: +65 6379 5261/2
Fax: +65 6475 2077
Email: admin@adi2009.org
Web: www.adi2009.org

28 – 30 May 2009
19th Alzheimer Europe Conference
Stars for Help
Brussels, Belgium
Tel: +32 2 512 4442
Fax: +32 2 502 4443
Web: www.alzheimer2009.eu

11 – 16 July 2009
International Conference on Alzheimer's Disease (ICAD)
Vienna, Austria
Tel: +1 312 335 5790
Email: icad@alz.org
Web: www.alz.org/icad

20 – 22 July 2009
International Associations of Homes And Services for the Ageing (IAHSA)
Leadership Beyond Borders
London, UK
Web: www.iahsa.net/london

1 – 5 September 2009
International Psychogeriatric Association 14th International Congress
Better Mental Health for Older People
Montréal, Canada
Tel: +1 847 501 3310
Fax: +1 847 501 3317
Email: IPACongress@ipa-online.org
Web: www.ipa-online.org

29 – 31 October 2009
III Congreso Iberoamericano de Alzheimer
San Juan, Puerto Rico
Tel: +1 787 727 4151
Fax: +1 787 727 4890
Email: alzheimerpr@alzheimerpr.org
Web: www.alzheimerpr.org

7 – 10 November 2009
12th Asia-Pacific Regional Conference of Alzheimer's Disease International
Lahore, Pakistan
Tel: +92 4275 96589
Fax: +92 4275 73911
Email: info@adi2009.org.pk
Web: www.adi2009.org.pk

2010

11 – 13 March 2010
25th Annual International Conference of Alzheimer's Disease International
Dementia: Making A Difference
Thessaloniki, Greece
Tel: +44 (0) 870 458 4171
Fax: +44 (0) 870 442 9940
Email: adi2010@mci-group.com
Web: www.adi2010.org



Now that I live with dementia

A speech by Heather Roberts at the launch of the National Dementia Strategy in the UK

I am Heather Roberts, 54, and I have Alzheimer's disease. I am an Ambassador for the Alzheimer's Society and I'm here telling my story. However, my story is not unique to me, thousands with dementia will all tell a similar story.

I was diagnosed at 50, after a three-year struggle. During my diagnosis no one listened, they just kept saying that I was depressed and that I had to take anti-depressants. In all I was forced to 'try' 7 different anti-depressants, none of which did me any good. Both the Neurologist and the Psychiatrist thought that 'I was too young to have a dementia'!! I had to fight to get any one to think about memory testing, and eventually my diagnosis was made on the basis of my declining scores from this testing. However, as the memory tests were only done once a year, and they required three distinct declining tests, it took at least two years to get the diagnosis on the basis of memory tests.

In a way it was a relief to have that diagnosis, now it felt that someone was actually listening and not just trying to force anti-depressants down my throat. I was now able to talk to my friends and family about my dementia diagnosis, and I was able to approach the Alzheimer's Society for some support. I was very lucky that when I was diagnosed I was prescribed Aricept. This has made a huge difference to my life; tests have shown that I have regained 2 years of mental decline. I am still able to enjoy a good quality of life, and I still maintain some independence, although I do have to be careful, as I do get confused at times. I am still driving, although my licence is reviewed on an annual basis, and I choose to drive where I feel confident

and at quieter times. People who receive a diagnosis today no longer can have access to these drugs at a time when they could gain the greatest benefit.

How does it affect me? First you have to have some insight as to the person I was. I used to be a payroll computer consultant, working within a very exacting industry. Now I can't add up, and I struggle with money. I get very confused and disorientated in noisy environments or where there are lots of bright lights. I can no longer make decisions as I cannot weigh things up or evaluate things. I have lost all of my emotions, and my personality is changing. It's as if I am losing parts of me very slowly, and becoming just a subset of myself. Fortunately the progression of this disease is slow for me, for others things happen at a very faster rate and they decline in a matter of just a few short years. But we have all been affected by the terrible stigma that surrounds dementia. I have lost count of the number of times people have said to me 'You don't look like you have dementia'!! Several of my friends and even family members have disassociated themselves from me, as they can't cope with the implication of the diagnosis. I have to use this time I have been given to its best possible usage; I have already started to think about planning for the End of Life and to consider an Advanced Directive.

I am very lucky in that Dave has been able to retire to support me and my family are old enough to understand what is happening to me. There are many thousands out in the community, living and coping with this dreadful disease on their own. Many more are without

a formal diagnosis because it is just too hard to fight the system. Most of us have to manage without the help and support of the existing care system. These people are the 'silent people' with dementia unknown to any formal system and missing from those guess estimates on numbers with this dreadful disease.

Meanwhile I keep busy, live life to the full, enjoy everyday and laugh a lot. We travel to those places I've always wanted to see. Exercise and healthy living all play their part, but most important, is to stay positive and fight to hold back the changes, always knowing that, realistically, that this disease will finally win. But I am going to go on, living life to the full with dementia, doing all those things from my wish list. I've stopped 'saving for that rainy day', now is the time to enjoy the fruits of the time that I have left.

This is my story describing what it is like to live with dementia. Now we are going to hear about the new National Dementia Strategy and how it's going to make a diagnosis and living with dementia easier and more bearable.

However, describing a much-improved world in a strategy document is not enough. Its success will be entirely down to it being implemented effectively. My challenge to you, gentlemen, is to ruthlessly make sure that it is. Thousands of people like me, and many thousands more who will go on to develop this horrible disease are depending on you.

You can download 'Living well with dementia: a National Dementia Strategy' from www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDementiaStrategy

Members' forum

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

MAURITIUS

The Alzheimer Association of Mauritius has sent us an update with pictures of their work. They renovated their building in September prior to the celebration of the World Alzheimer's Day. A consultation room has been created with a PC and printer, so they are now ready to receive patients for a proper consultation.

On 20 September a major event was organised at the centre and the event was covered by the National TV and local Radios and newspapers. The centre is now known as the 'Jean Vaulbert De Chantilly – Centre Alzheimer'. The telephone line was also activated and volunteers are responding to telephone calls from 9.00 to noon on Mondays, Wednesdays and Fridays.



AUSTRALIA

This Younger Onset Dementia Summit was held to promote awareness of younger onset dementia and to identify consumer needs and ways to improve social conclusion. The summit was hosted on 23-24 February by Parliamentary Friends of Dementia and Alzheimer's Australia in Canberra.

Over 100 people were at the summit – mainly people with younger onset dementia and their care partners – from across Australia. The summit produced an agreed Summit Communiqué. The communiqué and new publications on younger onset dementia prepared for the summit are at www.alzheimers.org.au/youngeronssetdementia

Six key issues were identified:

- Promote awareness of younger onset dementia. Increased awareness to reduce stigma and social isolation
- Timely and accurate assessment and diagnosis
- Access to age appropriate services
- Employment and financial issues
- Legal and bureaucratic issues
- Research

Delegates at the Australian Summit





Training session in Nepal



Rotary (Nepal)

NEPAL

One of our newest contacts is with the Alzheimer association in Nepal. Ajay Chettri, President of the association, sent us some pictures from a three day training seminar that was organised by Institute of

Medicine, Kathmandu and Connect for Change UK. Four doctors were invited from the UK. The Minister of Health inaugurated the training session. Policy makers' awareness of dementia is increasing in Nepal.

NETHERLANDS

From the beginning of 2005 till the end of 2008, the Netherlands conducted a National Dementia Programme (Landelijk Dementieprogramma or LDP) that was implemented in 57 regions. It was funded with 2.8 million euro from the government, involved 117 regional Alzheimer advocates and delivered 206 projects to improve dementia care around the country.

The project was structured by adapting the 'Breakthrough Method' that was developed by Harvard University, Boston USA. From 2005 on, in five stages, project teams were formed in

each region with representatives of people with dementia and their carers, health professionals, service providers and policy makers from health insurance companies and local governments. Based on panel sessions with people with dementia and carers their needs were reviewed. This resulted in local action plans, to be implemented by all the stakeholders in collaboration.

Julie Meerveld, project leader at Alzheimer Netherlands, said, 'It is interesting to see that every region in a way tried to find its own solutions and sometimes

reinvented the wheel. By doing this, they got ownership of their projects. Another key factor was the need of quantitative data on the main needs, so a standard questionnaire was developed. In many regions the main outcome of the project was the need to see dementia care as a chain of activities from early to late stages and the need to adjust a care manager to every family.'

Alzheimer Netherlands is now involved in the follow-up of these arrangements to ensure that the results will be implemented throughout the country.

UK

New catalogue of resources

The Alzheimer's Society (UK) recently opened a Dementia Knowledge Centre in its new office in St Katharine Docks, London. It brings together a large collection of information and knowledge resources about dementia in one place, in a dementia-friendly environment with study spaces and access to the internet. The centre is open to everyone with an interest in dementia care and research. Entry is by appointment.

For those not frequently visiting London (most of our readers!) there is another way to benefit from the work and resources of the Alzheimer's Society. The Dementia Catalogue is available on a free website which has 10,000 records – book, reports, journal articles, videos, DVDs and training resources.

See www.alzheimers.org.uk/dementiacatalogue

25 Years of ADI



**Alzheimer's Disease
International**

On 21 September 2009 – World Alzheimer's Day – ADI will be commemorating twenty-five years of hard work, support and bringing people together. The past twenty-five years have seen continuing progress for the worldwide dementia movement, with advances in research and medication and greater recognition from the World Health Organization. For ADI, the past twenty-five

years has seen growth in a number of areas: increasing membership of associations from all parts of the world; the launch of very successful advocacy and awareness programmes such as World Alzheimer's Day; and the development of support and information programmes, like the Alzheimer University, for ADI members. Here we look at how ADI has developed, changed and grown since its beginnings in 1984.

Sharing information

Providing information is an important part of ADI's aim to unite associations across the globe. The launch of the ADI newsletter, *Global Perspective*, in 1990 allowed members and others associated with ADI a way of sharing their views, activities and stories with others. *Global Perspective* has since become a popular way of providing updates from ADI, its members and the research field.

ADI's first booklet publication, *Help for Caregivers*, was launched in 1994. The booklet was created in partnership with the World Health Organization and, in 2000, a website based on the booklet was launched.

In 1997 ADI's website was launched, allowing anyone from anywhere in the world access to information on the organisation and its work. Also in 1997, the first ADI factsheets were produced along with the first Latin American bulletin.

With the introduction of the Alzheimer University in 1998 ADI was able to offer training programmes for emerging and developed associations, tailored to suit their individual needs. The Alzheimer University has continued to grow since its foundation: taking place outside of the UK for the first time in 2004; paying its first visit



ADI conferences offer a good opportunity to share information with others

to the Asia Pacific region in 2005; and venturing into topics such as advocacy and fundraising.

At the Council meeting in 2005 the ADI Twinning Programme was launched. The purpose of the programme was to bring two associations together, one developed and one developing, to exchange ideas and assist each other in developing new skills. The programme has been a great success in its first three years with the formation of a new charity, Friends of ARDSI, in the UK and opening of a new day care centre in Pakistan. This success looks set to continue well into the future.

Research

On 15 September 1989, the first steps towards bringing medical and research professionals together to establish a Medical and Scientific Advisory Panel (MSAP) were taken.

The aim of the panel was to provide advice and information when necessary and to represent ADI worldwide. Just four years after its launch, and with the election of Henry Brodaty as Chairman, MSAP had recruited over 100 medical professionals and researchers.

The work of the Public Policy Committee in 1993 provided ADI with their first results on the prevalence



Former ADI Chairmen Orien Reid, Henry Brodaty, Nori Graham and Brian Moss

ADI's current Chairman Daisy Acosta is hopeful that dementia will be recognised as a global health priority



Governance key dates

- 1984 Founding of Alzheimer's Disease International on 21 October
- 1984 Princess Yasmin Aga Khan elected President of ADI
- 1985 Executive Committee meet to draw up ADI's aims, objectives and bylaws
- 1986 'Alzheimer's Disease International, The International Federation of Alzheimer's Disease and Related Disorders Societies Inc.' (ADI) is approved

- 1990 Brian Moss is elected Chairman
- 1991 ADI's first logo is formally approved
- 1995 ADI secretariat moves to London
- 1996 Nori Graham elected Chairman
- 1998 ADI rebranded
- 2002 Henry Brodaty elected Chairman
- 2005 Orien Reid elected Chairman
- 2008 Daisy Acosta elected Chairman

of dementia. The information came from a survey conducted by the committee and sent out to ADI's member associations.

In 1998 the 10/66 Dementia Research Group was founded, comprised of a number of researchers with the aim of discovering more about the 66% of people with dementia whose situations had been covered by only 10% of previous research. The main points of focus for the group were the prevalence and risk factors of dementia as well as the care arrangements and support available in these developing countries. The 10/66 Dementia Research Group had the results of their first piece of

research published in *The Lancet* in March 2003.

Both MSAP and the 10/66 Dementia Research Group continue to provide updated and relevant information

and statistics, giving member associations, policy makers and the general public information about the circumstances of people with dementia and their carers worldwide.



10/66 research in Ibadan

■ Research update

Can lifestyle prevent Alzheimer's

Henry Brodaty

It's a tantalising tale but is it true? Can we really eat, drink, exercise, socialise and think our way out of Alzheimer's way? Are vitamins, Ginkgo, Brahmi, fruit/vegetable juice and red wine the elixirs for youthful brains? Or, is it all too late? Are the tangled ravages described by Dr Alois Alzheimer 103 years ago determined by our genes and hard-wired into our brains from our conception?

The answer is yes ... and no. Genes are important but not enough. For most people, certain genes increase the risk but do not necessarily cause the disease and Alzheimer's disease can develop without these genes.

So environment is important but which elements are protective and which are hazardous? The evidence largely comes from population or epidemiological studies and from laboratory work in test tubes or with animals, usually mice.

Retrospective epidemiological studies look back at populations and compare two similar groups of people, one with Alzheimer's disease and one without, for their past experiences and habits such as previous head injury, past use of alcohol, food preferences or exercise routines.

A second epidemiological study design is prospective, looking forward. This method follows up two groups of people, one who are exposed to a risk or protective factor of interest and another who are not. For example, when

women who were taking hormone replacement therapy (HRT) and a similar group who were not taking HRT were regularly examined over a number of years, those on HRT had a lower rate of Alzheimer's disease.

Epidemiological studies have reported protective effects for education, regular physical exercise, mental activities, fluids rich in anti-oxidants and polyphenols such as fruit or vegetable juice, wine and (green) tea, fish, long-term use of certain medications – non-steroidal anti-inflammatory drugs (NSAIDs such as Indocid, Voltaren), anti-cholesterol drugs (statins such as Lipitor, Locor, Zocor) and hormone replacement therapy. The flip side is that high blood pressure, diabetes (type II), obesity, high fat diets, high cholesterol, head injury, loneliness, lack of education, lack of exercise, depression, low birth weight for gestational age and smaller head circumference have been found to be risk factors.

But beware of headlines that proclaim that doing crosswords, 2-3 glasses of wine or 3-5 cups of coffee a day can prevent Alzheimer's disease! These findings are suggestive but not proof. The gold standard is a randomised controlled trial in which one group of people is randomised so that, say, half receive the intervention – for example, a drug or exercise – and the other half do not – for example, they take a placebo or perform usual activities. When examined in this more rigorous way,

hormone replacement therapy in women aged 65 or more was found to be a risk factor for Alzheimer's disease completely overturning the epidemiological findings. Neither anti-inflammatory drugs nor Vitamin E has been confirmed to be protective and anti-inflammatory drugs can have significant side effects. Ginkgo biloba was reported a few months ago to have no preventative effect. There has been no adequate trial of Brahmi. On the other hand, a randomised controlled trial of walking three times a week by people aged 65 or more demonstrated improvement of cognition over 12 months compared to controls who continued usual lack of exercise.

Research in test-tubes and with animals can provide important clues to prevention and treatment. Mice genetically engineered to develop Alzheimer's disease, produce less Alzheimer pathology in their brains if they are reared in a more physically and socially stimulating environment. The finding that curcumin, an ingredient of curry, can prevent the build up of the toxic amyloid β protein in test-tubes has led to randomised controlled trials of its use in humans. Vaccines that work well in test-tubes and in mice are undergoing trials for treatment of Alzheimer's disease.

The bewildered consumer should note several important points. Firstly, there is no absolute prevention against Alzheimer's disease. Secondly, prevention often means postponement rather than eradication of the disease. This is of

disease?

great consequence as Alzheimer's disease is a condition that comes on at the end of life for most, so delaying onset of Alzheimer's disease by five years is reported to reduce the number of cases by half. Thirdly, until reports are confirmed by a number of groups around the world, consumers should be wary of media hyperbole.

Fourthly, even where a risk or protective factor is shown to be significant, this only changes the risk slightly. Type 2 diabetes is confirmed as risk factor but most people with diabetes don't develop Alzheimer's disease. A small percentage change in rate of development of disease in a large population will be statistically significant for the group as a whole but will increase the chances only slightly for an individual.

Future research will require more complex methodologies. Are there gene-environment interactions? Factors such as exercise or diabetes that change the risk of Alzheimer's disease may only do so if a person has a particular gene (such as ApoE4) and may differ for men and women. There may be a dose effect so that a little alcohol is thought to be good but too much is definitely bad. But for other factors such as anti-oxidants, only higher doses may be effective.

What should we all do? The best evidence for prevention is regular physical exercise, mental activity and blood pressure control. In general, what is good for your heart is good for your brain.

Alzheimer's Australia's seven step Mind your Mind program to prevent Alzheimer's disease is recommended (see box). I would add an eighth step: Don't worry. It doesn't help.

It's facile to think that meeting your friends for a game of bridge at the pub while eating fish and drinking wine will definitely prevent Alzheimer's disease, but it is fun and it may delay the onset.



Alzheimer's
Australia
Living with dementia

- 1 Mind your brain**
Use it or lose it – play bridge, do crosswords
- 2 Mind your body**
Take regular physical exercise
- 3 Mind your health checks**
Monitor and treat high blood pressure and cholesterol
- 4 Mind your diet**
Avoid fatty foods and obesity, eat fish and food rich in anti-oxidants
- 5 Mind your habits**
No smoking, moderate alcohol
- 6 Mind your head**
Protect your head from injury – wear a helmet if riding a bicycle
- 7 Mind your social life**
Socialise regularly

For more detail see www.alzheimers.org.au

ADI–FMA Award for Psychosocial Research

Together with the **Fondation Médéric Alzheimer (FMA)**, a non-profit organisation from France dedicated to people with Alzheimer's disease and their carers, ADI has launched an Award for Psychosocial Research.

The aim of this award is to promote research in this area and the application of best practice. People with dementia, their carers and also institutions can benefit from this research with effective intervention programmes to improve daily living.

The reward will be a prize of €25,000 to be used for dissemination of the research findings of the winner to a broad range of those involved in dementia treatment and care.

A call for proposals for this award was sent out last autumn and a jury reviewed the submitted proposals. Members of the jury were: Henry Brodaty and Antonio Leuschner, both researchers; Myrna Blake, a person with dementia; Helen Lim, a caregiver; Kevin Charras on behalf of the Fondation; and Marc Wortmann of ADI.

Out of the fourteen proposals received, five were short listed for a final decision. The other nine proposals were all interesting but did not fit the award criteria, mostly because the research was not completed at the time of submission.

We do understand that in countries with emerging Alzheimer associations, research on psychosocial interventions still needs to be implemented. However, these proposals indicate a renewed interest in this field around the world.

We now present a summary of the five proposals that reached the final stage. The winner will

be announced during the ADI conference in Singapore.

ALEXANDER KURZ
Technische Universitaet Muenchen: Cognitive-behavioural resource oriented treatment of early dementia in everyday life (CORDIAL).

This is an intervention for patients at the early stage of Alzheimer's disease. It includes 12 weekly sessions where patients are encouraged to establish and implement behavioural routines, which enhance and maintain daily functioning as well as active coping. Carers are systematically involved. The outcome measure is the patients functioning on activities of daily living, at baseline, at the end of the intervention and six months after the intervention. The study was performed in 10 centres in Germany. As a long-term outcome it is intended to incorporate the cognitive-behavioural therapy into the standard treatment scheme for patients at the early stage of Alzheimer's disease.

DANNY GEORGE
The Intergenerational School: Can Intergenerational Volunteering Promote Quality of Life for Persons with Mild to Moderate Dementia?

From the hypothesis that intergenerational volunteering would enhance quality of life, fifteen residents of an assisted living facility in Cleveland, Ohio, were randomised into two groups. One group volunteered weekly in a school in a variety of

activities in kindergarten and with older students. The other group participated in an educational seminar at the assisted living home over the same interval. Quality of life was measured by aggregating scores on psychometric tests and by analysing qualitative data collected during the 10-month study. Ultimately, the intervention group showed a statistically significant reduction in stress, a lower mean decline in cognitive functioning compared with the control group, and comparatively higher scores for sense of purpose and sense of usefulness. The study suggests that intergenerational volunteering may promote quality of life for persons with mild to moderate dementia through a variety of bio-psychosocial pathways – particularly stress reduction – and confirms that older persons challenged by memory loss can still make major contributions to their community.

MARY MITTELMAN
NYU School of Medicine: Translating the NYU Caregiver Intervention from Research to Practice Settings.

This project began in the 1980s and still continues. It was designed to mobilize the support of family networks, improve caregiving skills and provide the opportunity for counselling as needed over the entire course of caregiving. The treatment group received six sessions of individual and family counselling within a 4-month period, agreed to join support groups and could contact the

counsellor for additional help. The control group received the usual care offered to family members. The intervention has proven efficacy in improving caregiver support and physical health and reducing depression and problem behaviours, even years after.

VINCENT ANTENUCCI
Hearthstone Alzheimer Care:
Translating Alzheimer's
Research into Practice
through an Online Information
Marketplace and Exchange.

The proposal is on creating a new mechanism for ongoing dissemination of research-based interventions and techniques, including those currently available, under development or yet to be discovered. The Online Information Marketplace and Exchange is designed to be available for scholars, healthcare professionals, caregivers, and others interested in improving the quality of life of persons with Alzheimer's disease and other dementias.

EMMELYNE VASSE
Interdem Group: Improving
the quality of psychosocial
dementia care in Europe
through evidence-based
practice: developing a set
of quality indicators for
implementing a tool kit of
interventions.

After reviewing a large number of psychosocial interventions, the group has developed a set of quality indicators for psychosocial care in dementia. The aim of the project is to validate the quality indicators within a pan European pilot investigation, so finally policy makers and health care professionals will have an instrument to examine implementation of evidence based recommendations.

Obituary

Jeanne Bentley of Calgary, Alberta, Canada

By Debbie Benczkowski

Hazel 'Jeanne' Bentley was a pioneer and early advocate for people with Alzheimer's disease. Sadly, Jeanne herself was diagnosed with Alzheimer's disease, and died on Tuesday February 17, 2009. Jeanne is survived by her husband Bob; and her daughter Pam. Bob and Pam took loving care of Jeanne while she lived at home, and most recently, spent many hours with her after she moved to a care facility last Fall. Unfortunately, on February 2, Jeanne had a fall and broke a rib, which nicked her lung. She was put on oxygen (full time) with painkillers and extensive care. On February 15, she started rapidly deteriorating and passed away on February 17. Her daughter, Pam, was with her when she died. Bob has also had health challenges, and had a heart attack on 9 February. He only returned home from the hospital the day after Jeanne passed away.

Jeanne's father, Graeme, was diagnosed with Alzheimer's in 1981. In true Jeanne Bentley fashion, Jeanne didn't sit still and just accept her father's diagnosis. Jeanne, along with ten other caregivers, came together and founded the Alzheimer Society of Calgary. Over the next twenty years, Jeanne continued to volunteer in the Alzheimer world, serving in many capacities, including, President of the Alzheimer Society of Calgary and then of the Alzheimer Society of Canada. Jeanne was also very active in Alzheimer's Disease International, attending many conferences over the years, and serving as chair of the 1993 ADI Conference in Toronto.

In the eulogy at Jeanne's funeral, her daughter Pam recalled a letter she recently found from her mother, describing the 1993 conference, her last as national president. She was proud of its great success, and was particularly thrilled that the line dancing she had suggested for the gala banquet was such a big hit with the delegates.

Pam also talked about how she remembered her mom, and said that when she thought of her, she thought of someone who was always busy, who just wanted to help out and be useful. Going through the books beside her bed a few months ago, Pam came across a book she'd given her more than a decade ago: *Meditations for Women Who Do Too Much*. It didn't look like it had ever been opened.

There are so many things about Jeanne that her family would want you to remember about her – she loved to laugh, and wore purple when she could, she told a good story, and enjoyed one too, especially over a beer at the end of the day. She liked the adventure of learning and finding new things. She loved to sing and to dance and to create beautiful things and to make things grow. She was still singing right up to her death. Jeanne always noticed the colour of the sky, even when she would struggle for the words to describe it. She loved the mountains and playing tour guide in her native Alberta.

Thank you Jeanne, for all you did and all you gave. You will be missed.

25th International Conference of ADI Thessaloniki, Greece 10–13 March 2010

Dementia: Making a difference



PHOTO: NICK KONTOU

Plans are already well under way for ADI's next international conference in Greece in 2010.

We have been working hard to develop a diverse and interesting programme based on the theme 'Dementia: Making a difference'.

The programme focuses on the latest developments in medical treatments, non-pharmacological interventions and prevention, as

well as sharing best practice in care. As we see more and more countries successfully bringing dementia to the attention of governments and public health bodies another exciting part of the conference will celebrate these successes and look at how this can be built on to make dementia a global health priority.

We encourage everyone to be a part of this great programme, to share

your knowledge and new ideas. Abstracts can be submitted online from 2 May 2009. A list of the abstract topics and more detail on the programme can be found on the conference website at www.adi2010.org

Registration will open on 1 June 2009, but to be sure not to miss out on the latest conference news why not register your interest now on the conference website?

ADI and the Greek Association of Alzheimer's Disease and Related Disorders look forward to welcoming you to the beautiful port city of Thessaloniki, Greece for what will certainly be a lively and interesting conference!

Future ADI conferences

The 26th International Conference of ADI will be held 26-29 March 2011 at the Sheraton Centre Toronto Hotel in Canada. ADI and the Alzheimer Society of Canada are looking forward to bringing you a great conference. More information can be found on the conference website at www.adi2011.org



Thessaloniki, Greece

World Alzheimer's Day 2009

Every 21 September ADI and its members across the globe organise events and activities to mark World Alzheimer's Day. The theme for this year's World Alzheimer's Day is 'Diagnosing Dementia: See It Sooner'. This year ADI is asking its members to focus on the importance of getting a diagnosis, while urging medical professionals to diagnose dementia as a first step to help.

Materials for this event will be available for members to order in May. We will give more details about plans for World Alzheimer's Day 2009 in our next issue.