



# Global Perspective

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



## The Alzheimer University Second course a great success

Alzheimer's Disease International held its second Alzheimer University course for representatives of Alzheimer associations at the end of June in London. The weekend was a great success and brought together key individuals from emerging Alzheimer associations in Egypt, Lebanon, Malaysia, Russia, Slovakia, Thailand and Trinidad and Tobago.

'The structure of the workshops were excellent as everybody was involved' said Alexander Mitro from Slovakia. Norma Inniss (pictured above) from Trinidad and Tobago added 'the inclusion of the visit to the day care centre was an excellent idea.'

The course has been devised as a series of workshops and is aimed at

giving participants the skills to get their association off the ground. Workshop topics included identifying aims, providing information, developing support groups, recruiting volunteers, raising money and raising public awareness. The course finished with visits to day care centres run by the Alzheimer's Disease Society, UK in London. Funding was provided by Janssen Pharmaceutical and the Wingate Trust.

Participants are formally followed up after six and twelve months to see how they are getting on and are encouraged to keep in touch with ADI throughout the year and beyond. It is hoped that all seven countries will become members of ADI.

ADI is now considering the expansion of the Alzheimer University to include 'train the trainer' workshops. These will enable organisations to run their own version of the course. Module two of the Alzheimer University course will be run during ADI's annual conference in Johannesburg. This module is aimed at strengthening the work of existing associations.

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Participants and organisers at The Alzheimer University



## ANNOUNCEMENTS

1999

**15-20 August  
9th Congress of the  
International Psychogeriatric  
Association**

Challenges for the New  
Millennium: Professional, Cultural  
& Regional Diversity  
Vancouver, Canada  
Tel: +1 604 681 5226  
Fax: +1 604 681 2503  
Email: congress@venuewest.com

**25-28 August  
3rd Alzheimer Congress of  
Brazil**

Sao Paulo, Brazil  
Tel/fax: +55 11 288 7428  
Email: abraz@wm.com.br

**16-18 September  
Alzheimer's Disease  
International 15th  
International Conference**

Dementia, Challenge of our Time,  
Creating Hope for the New  
Millennium  
Johannesburg, South Africa  
Tel: +27 21 762 8600  
Fax: +27 21 762 8606  
Email: adi99@globalconf.co.za  
Web: www.globalconf.co.za/adi99

**16-17 September  
World Federation of Neurology**

Johannesburg, South Africa  
Tel: +1 414 454 5224  
Fax: +1 414 259 0469  
Email: antuono@mcw.edu

**23-25 September  
Alzheimer's Association  
Australia National Conference**  
The Tapestry of Care: Creating a  
Pattern for Dementia Management  
Near Perth, Australia  
Tel: +618 9332 2900  
Fax: +618 9332 2911  
Email: promaco@promaco.com.au  
Web: www.promaco.com.au

**1-2 October  
2nd Leonard Berg Symposium  
on Alzheimer's Disease**  
Mild Cognitive Impairment:  
Relationship to aging and incipient  
Alzheimer's disease  
St. Louis, USA

Tel: +1 314 286 2881  
Fax: +1 314 286 2763  
Email: ADRCedu@neuro.wustl.edu  
Web: www.adrc.wustl.edu/adrc/  
symposium.html

**3-6 October  
The First International  
Congress on Vascular  
Dementia**

Geneva, Switzerland  
Tel: +41 22 908 1855  
Fax: +41 22 908 1835  
Email: vascular@kuoni.ch  
Web: www.kenes.com/vascular

**5-9 November  
Alzheimer Association  
National Leadership  
Conference**

Charging leaders for changing  
times  
Nashville, USA  
Tel: +1 312 335 5762

**12-14 November  
European Reminiscence  
Network Conference**  
Remembering yesterday, caring  
today  
Stockholm, Sweden  
Tel: +44 20 8318 9105  
Fax: +44 20 8318 0060  
Email: age-  
exchange@lewisham.gov.uk

2000

**29-31 March  
3rd Latin American and ADI  
regional meeting**

Havana, Cuba  
Tel: +53 7 552 164 extn 1514  
Fax: + 53 7 228 382  
Email:  
zosima@paclco.get.cma.net

**9-18 July  
World Alzheimer Congress  
2000**

Pivotal Research and Creative  
Care  
9-15 July comprises the 7th  
International Conference on  
Alzheimer's Disease and Related  
Disorders. 15-18 July comprises  
Alzheimer's Disease International's  
16th Annual Conference  
Washington, USA

## International directions

DR JACOB ROY, CHAIRMAN, ALZHEIMER'S DISEASE AND RELATED DISORDERS  
SOCIETY OF INDIA (ARDSI) AND VICE CHAIRMAN OF ADI



It has been ten months since the 14th ADI conference in Cochin, India. This 'once in a life time experience' for ARDSI has completely changed the face of dementia in India and what was once an unknown condition has now gained acceptance by the public and professionals, and is supported by the press.

This has given ARDSI the confidence to embark on larger projects, such as setting up the Indian Institute of Dementia Care, Training and Research at Cochin. It is hoped that the first phase of this national referral centre will be completed within three years.

Two members of ARDSI have been invited by the Alzheimer's Disease Society to spend two weeks visiting dementia care services in the UK. The Swiss Alzheimer's Association has also extended support to train more community geriatric nurses. ARDSI are organising a regional conference in Bangalore in August as well as the 5th national conference in October. ARDSI will also be participating in the second meeting of the ADI Asia Pacific dementia group in Singapore.

At a national level, welfare and health government departments are showing interest in supporting dementia projects. ARDSI are concentrating on strengthening the work of existing chapters before setting up new ones.

Organising the conference was a big challenge and looking back, we feel it was worth it. It has opened up new opportunities and has given us the confidence to face the challenges that lie ahead.

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Fax: +1 312 335 1110  
Email: alzheimer2000@alz.org  
Web: www.alzheimer2000.org

**12-15 October  
10th Alzheimer Europe  
Meeting**  
Bridges into the Future  
Munich, Germany  
Tel: +49 89 210 986 0  
Fax: +49 89 210 986 98  
Email: info@eurokongress.de

Fax: +44 1752 202 331  
Email: orders@plymbridge.com

**Clinical Diagnosis and  
Management of Alzheimer's  
Disease Second Edition**

By Serge Gauthier  
£65 available from Martin Dunitz  
Publishers, The Livery House, 7-9  
Pratt Street, London NW1 0AE  
Tel: +44 171 482 2202  
Fax: +44 171 482 7088  
Email: arbl@globalnet.co.uk

## PUBLICATIONS

**Managing Alzheimer's  
Disease in Primary Care**  
By Henry Brodaty.  
ISBN: 1-85873-312-X. £12.95  
available from Plymbridge  
Distributors, Estover Road,  
Plymouth, Devon, PL6 7PZ, UK  
Tel: +44 1752 202 301

**Alzheimer's Disease in  
Primary Care Second Edition**

By Serge Gauthier  
£9.95 available from Martin  
Dunitz Publishers, The Livery  
House, 7-9 Pratt Street, London  
NW1 0AE  
Tel: +44 171 482 2202  
Fax: +44 171 482 7088  
Email: arbl@globalnet.co.uk



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Internet: www.alz.co.uk

## Mailing list

If you would like to receive this newsletter, please give the Secretariat your details. There is no charge, but donations are always welcome.

## Send us your comments

If you have any comments about or items for the newsletter (we are particularly keen to hear from carers) please contact the Secretariat.

## Put your requests for help in Members' Forum

Member countries requiring help or information are asked to put their requests in writing for inclusion in Global Perspective.



## A carer's story from the UK

# Coping with Alzheimer's disease



Watching the person you love turn into a stranger is one of the hardest things to bear. Cyril Kates, 87, is an active member of the East Devon branch of the Alzheimer's Disease Society in the UK. He tells how he knew that something was wrong with his wife Mary when the washing up started to be left and the dust appeared, and talks fondly about the woman he has loved for more than half a century.

'Mary was always very meticulous about housework. Not obsessive but proud of her home. I wasn't allowed to do anything in case I got it wrong. That was why it was so noticeable. In the early days sufferers are masters at making excuses but when things like the cooker were left on and the telephone left off the hook I knew it wasn't right.'

Gradually things got a lot worse. Mary would wander out of the house

and get lost and for a long time she called her husband by his sister's name. 'At the time it was most distressing. In the end I got so upset I told her off and it stopped.'

Cyril and Mary lived in Australia for many years. They had moved there to be near their son but were eventually told they could no longer remain, and so returned to Devon.

'Now apart from eating bananas first thing in the morning, she does absolutely nothing. I get very sad sometimes because she is living in a fantasy world. Then all of a sudden there is a gem, a memory comes out and that is wonderful. It makes everything else easier to cope with. There are some people she recognises, I can tell by her eyes, they smile, and she is great friends with our neighbour. She is about the only other person who Mary actually talks to.'

Mary, who is 88, still lives with Cyril but he misses the woman she used to be. 'It's those sparks, when the brain comes alive – they make the difference.'

## The Eurocare study: extending the scope

Some readers will have heard about Eurocare, a European study of the experiences of spouses caring for partners with dementia. Since presenting the findings at the 8th Alzheimer Europe conference in Lucerne, we have been contacted by a number of national associations who wished to repeat this project among their own memberships.

In the Eurocare study, researchers in each of 14 European countries interviewed 20 spouse carers about the difficulties experienced, family support and the reactions of others to their spouse's illness, health and social services received, and positive aspects of caregiving. We also used reliable measures of mental health and carer 'burden'. Results indicated that in each country the level of 'burden' and distress in spouse carers was similar. Statistical analysis showed that feelings of burden were closely associated with behaviour problems in the ill

spouse, with the belief that others react negatively and with feelings of financial dissatisfaction. Two papers are to be published in the next few months in the *International Journal of Geriatric Psychiatry*.

Small scale local research projects are an excellent method of collecting information on the experiences and needs of local carers. The findings can be published in the local press to promote awareness of Alzheimer's disease and the role of the local association. During the ADI conference in Johannesburg in September we are hoping to encourage some of the newer associations to undertake their own surveys.

*If you like to participate in your own EURO CARE survey, please contact Joanna Murray at Institute of Psychiatry, De Crespigny Park, London, SE5 8AF. Tel: +44 20 7919 3150, email: spjujom@iop.bpmf.ac.uk*

# Members' Forum

## CANADA

### *Public Policy Day – making inroads for action*

The Alzheimer Society of Canada has conducted a four year public policy campaign directed at the federal government to raise awareness of Alzheimer's disease. Last April the Society held its 21st annual conference in Ottawa, and took the opportunity to discuss public policy initiatives with members of the federal parliament (MPs).

Caring and curing were the issues highlighted this year. Under the banner of caring, attention was drawn to the need for a national homecare program. With half of the 300,000 Canadians with Alzheimer's disease living at home, the current patchwork of homecare programs cannot meet the current pressures nor will it withstand the increasing demands that Alzheimer's disease is going to put on our system in the next millennium. The Society believes the federal government should put a national homecare program on the political agenda and should set national standards for homecare in Canada. The curing message highlighted the need to make research into Alzheimer's disease a higher federal priority.

In addition to these two critical issues, the strategy included a call for MPs to participate in a group called The Ottawa Circle, a non-partisan group of federal politicians who are dedicated to playing a leadership role in helping the Society.

The public policy day was attended by 300 Society staff and volunteers. The day opened with an address from the Parliamentary

Secretary to the federal Minister of Health and included presentations on the changing health-care system in Canada and influencing public policy during a transition period. These presentations were followed by several regional Alzheimer Society representatives who relayed their strategies and success stories of making inroads with policy makers.

Afterwards Society representatives met with their MPs, armed with a one-page 'leave behind' on the caring and curing issues, a fact sheet on Alzheimer's disease and the Society, and a packet of forget-me-not seeds. Of more than 50 visits, half resulted in MPs willing to join the Ottawa Circle. It was also discovered that many MPs had a personal connection to Alzheimer's disease.

The public policy day was very successful and made some significant headway in encouraging action from the federal government on the issues of Alzheimer's disease.

## NEW ZEALAND

### *Focus on support groups in the southerly regions of the southern hemisphere*



Kaitia Support group is attended by carers who travel long distances around the far North of the North Island of New Zealand. The meet once a month. The support group is part of the services provided by the Alzheimer's Society of Northland based in Whangarei. A community support worker facilitates the meetings and distributes resources. Because of geographical isolation it can be difficult for

carers to attend support groups as they are unable to make care arrangements. To overcome this support group meetings in the future will also include the person with dementia so that carers are better able to attend the meetings.

In Invercargill, a city in the most southern region of the South Island of New Zealand, the local Alzheimer's Society of Southland, organises monthly support groups and meetings. An annual educational day is held by the Society, which has been going for three years and has 37 active members. Despite being a mere 5000km from the South Pole the Society still feels part of the national and international scene.

## MEXICO

### *Second Latin American regional meeting. Mexico, March 1999*



The second annual regional meeting of ADI's Latin American members was hosted by AMAES, the Mexican Alzheimer's association in Oaxaca, Mexico, in March.

Eleven ADI members in the region were represented at the conference. Lively workshops and round tables enabled members to update each other on their activities and learn from one another in a common language. Topics addressed included how Alzheimer associations can work with professionals, the impact of dementia on carers and ADI's Alzheimer University. The meeting was run in parallel with the first Latin American Meeting of the Ageing Brain.

All the delegates enjoyed the warm and generous hospitality of

the Mexican hosts which included a special reception at the historic cathedral of Santo Domingo and an evening torchlit procession through the streets of Oaxaca.

The third ADI Latin American regional meeting will be in Havana, Cuba March 29-31 2000.

### GUATEMALA

ERMITA's Distance Education Programme featured in the last issue was launched on 19 June. Over 400 people attended the opening ceremony, and the event received wide media coverage.

ERMITA would like to thank those who helped the project by making a donation.

### UNITED KINGDOM

Congratulations to the Alzheimer's Disease Society, which celebrated its 20th anniversary by hosting the 9th Alzheimer Europe in London at the beginning of July. The conference, entitled 'A meeting of Minds', was a huge success and was attended by over 600 delegates from 34 countries. The conference was truly a meeting of minds, bringing together professionals and



carers from not just Europe, but Trinidad and Tobago, India, Thailand and Cuba. Key speakers included Gabriella Salvini Porro, Alexander Kurtz, Mary Marshall and Peter Whitehouse.

## EMERGING ALZHEIMER ASSOCIATIONS

### RUSSIA

The Association for Support of Alzheimer's Disease Victims in Russia have been registered as a charity since April 1995. The Association, set up by professionals and carers, is based in Moscow and has a branch in Tver. Its main aims are: to unite the efforts of medical professionals with carers, as well as with social workers and the media; to improve the quality of life and provide support for people with Alzheimer's disease, their carers and families; and to support research.

The Association has already organised several conferences in Moscow and a symposium in Tver. The first of these was attended by over 200 members of the public. Several support groups for carers have also been set up. The Association has developed a model for a regional centre providing social, medical and psychological support for older people with mild cognitive and stress-related disorders. As a result of this, recommendations for the development of more centres have been put forward to the Government. Unfortunately the recommendations have yet to be recognised due to

the financial crisis in Russia.

The Association has been raising awareness by publishing articles in daily newspapers and magazines and through radio and TV reports. Currently the Association is preparing to hold the 2nd Russian Conference on Alzheimer's Disease and Related Disorders, 18-20 October.

Two members of the Association also participated in this year's Alzheimer University course, gaining useful and valuable experience to further develop the work of the Association. They plan to encourage and organise the formation of new self-help groups in other regions of Russia during the conference.

If you would like to receive more information about the conference or know more about the Association, please contact: Professor GavriloVA, Kashirskoye Shosse, 115522 Moscow, Russia: Tel: (095) 324 9615; Fax: (095) 114 4925; Email: gavriloVA@dionis.iasnet.ru

### PHILIPPINES

The Alzheimer's Disease Caregivers Society in the Philippines had their first meeting last March. Around 34 caregivers and their families attended. Dr Eduardo Poblete, geri-

atric fellow at St Luke's Medical Centre, was guest speaker at the meeting, which was held in the HI-Eisai building in Manila.

During the meeting Florentino Gandara introduced the Alzheimer Disease Caregivers Society by firstly defining the Society and then outlining its objectives. Their objectives include discussing effective ways of caring for people with Alzheimer's disease, forming self-help groups, and deciding the Society's role in disseminating information. The audience were then asked their expectations of the meeting, and to think about how they could contribute to making the society successful.

During the meeting, HI-Eisai reiterated that they will facilitate the first four or five meetings, and then will only assist the Society in subsequent meetings. It was agreed that an officer and secretary be appointed at the next meeting, which have been scheduled at monthly intervals.

The meeting ended with a message from the sponsor Mr Chito Limson, who thanked everyone for attending and encouraged everybody to actively participate in future activities to help develop the Society.

# 10/66 Dementia Research Group

**Less than one tenth of all population-based research into dementia has been directed towards the two thirds or more of all people with dementia who live in developing countries, hence the name 10/66.**

10/66 are a group of researchers who have linked together to try and redress this imbalance, encouraging active collaboration between research groups in different developing countries and between developed and developing countries.

The group is affiliated to ADI and is co-ordinated through Dr Martin Prince at the London School of Hygiene and Tropical Medicine. The aims of the group are:

- to quantify the prevalence and incidence of dementia in those countries and regions that have not been studied
- to learn more about the causes of dementia
- to describe care arrangements for people with dementia
- to quantify the impact of providing care on caregivers
- to encourage the development of appropriate support services and evaluate their effectiveness.

The 10/66 group had their first meeting at the annual international conference of ADI held in 1998 at Cochin, Kerala, India. During this meeting the group decided to focus on two small-scale achievable pilot study designs.

The studies address (i) education and culture for dementia diagnosis and (ii) care arrangements for people with dementia. Plans are well under way to carry out these pilot studies in multiple centres in Brazil, Dominican Republic, India, Sri Lanka, China and Japan.

People at these centres have been trained, or are about to be trained, in the use of key instruments and in most cases have begun to recruit suitable subjects. Other countries expressing



## Essential reading for all those working with people with dementia

The Journal of Dementia Care is published six times a year. For details of subscription and how to get a free trial issue, contact:

Dementia care  
Esco Business Services  
Robjohns Farm  
Vicarage Road  
Finchingfield  
Essex CM7 4LJ  
Tel: +44 1371 810433

interest are Nigeria, Mexico, Trinidad & Tobago, Singapore and Hong Kong. It is hoped to have as much of the data as possible in by the end of the year. The studies will provide the first data on care arrangements and their consequences for carers in Latin America, the Caribbean, Africa and South East Asia.

So far the Brazilian centre has been awarded a grant from the Sao Paulo state funding agency to carry out two pilot studies. In the Dominican Republic a team of psychiatrists and neurologists have been recruited to help with the recruitment of older people with dementia. There are seven centres in India involved in the group and five of these, along with Sri Lanka, met with Martin Prince to plan a concerted effort on the two pilot studies in March.

Two regional networks have begun in India and Latin America and the Caribbean. Regional networks are better placed to approach regional funding agencies, to organise research symposia and workshops and to facilitate communication.

The second annual meeting of 10/66 will be held in Johannesburg, South Africa during ADI's annual international conference in September 1999.

The group is now considering the next phase of research to follow on from the successful completion of the pilot studies and will be looking for funding to develop their work.

*If you would like more information about the work of the 10/66 group please contact:*

*Dr Martin Prince  
Epidemiology Unit  
London School of Hygiene and Tropical Medicine  
Keppel Street  
London WC1E 7HT  
Tel: + 44 171 580 6897  
Fax: + 44 171 277 0283  
Email: m.prince@iop.kcl.ac.uk  
Web: www.alz.co.uk/1066*

# Change of Mind

## The video training pack



**C**hange of Mind is a play about Alzheimer's disease by British writer Peter Spafford and performed by mind the... gap, a performing arts company based in the UK. The live performance of the play received wide acclaim and has now been brought to video with an accompanying training booklet, written by Sue Heiser and Sally Knocker.

Seen through the eyes of family members, Change of Mind tells the story of the Taylor family whose lives are changed forever when Doug is diagnosed as having Alzheimer's disease. Participants are drawn into the lives of four key characters over a seven year period, charting the development of the illness from before diagnosis to the very late stages. The play explores the changing dynamics of their relationships, interventions by a range of professionals and ethical dilemmas, and engages the viewer both intellectually and emotionally. Because of the powerful content of the play, an experienced and well-prepared group facilitator is essential.

The uniqueness of this training tool is in its ability to convey the entirety of the experience and particularly the emotional impact of dementia in just over an hour's

video time. Whilst the play is about a white family in the north of England and does have some specific references to the British community care system, it will undoubtedly have relevance and interest across English speaking countries. The symptoms of dementia, individual emotions and family relationships portrayed ensures that it can and should speak to a large audience. The training booklet includes discussion items, topic-based exercise and learning points and gives detailed guidance on its use for different groups – including care workers, volunteers, managers and students.

It is hoped that this excellent new training tool will do some travelling and reach a wide range of continents in the year ahead. Feedback to 'mind the...gap' on its use and relevance in different countries would also be much appreciated.

*The video training pack costs £116.33 plus postage and packing. It can be ordered from:*

*Mind the...gap  
Queens House, Queens Road,  
Bradford BD8 7BS.  
Tel: +44 (0)1274 544 683.  
Fax: +44 (0)1274 544 501  
Email: publishing@  
mindthegap.demon.co.uk*

# Spotlight on South Africa hosts of this year's ADI conference



Workers and users at A Re Tswaraneng

A Re Tswaraneng is an outreach project established in 1997 by Mothwa-Haven old age home, Pretoria, and is situated in Soshanguve, one of the poorest areas in Gauteng province 35km north of Pretoria. Soshanguve consists of both formal and informal settlements. Taxi violence, a high poverty rate, crime, unemployment, and family violence are typical social problems.

The homecare service of A Re Tswaraneng is addressing the needs of the 15,700 people aged over 65 in Shoshanguve. No other structured service is available for this target group. Existing welfare services are aimed at child and family care.

A Re Tswaraneng works in close conjunction with the South African Police Services, recognised community leaders, volunteers and the Alzheimer Related Disorders

Association of South Africa (ARDSI).

The main aims of the service are: to alleviate poverty; to ensure the elderly experience happiness, are empowered to generate some income and are assisted to improve their health conditions; and to raise awareness about dementia and its increasing prevalence in the community.

The service was first set up under a tree next to the police station. Since then a hut has been built on the same site. Now the project provides:

- meals three times a week for 150 people
- basic health services
- referrals to doctors and hospitals
- exercise and health education.

A team of 20 volunteers work to befriend and support families caring for someone with dementia, organise a second hand clothes sale every four months so older people can buy clothing cheaply, and organise income-generating activities such as baking and selling biscuits.

A Re Tswaraneng is a service which is expanding daily as the needs of the elderly of Shoshanguve, once overlooked, are now being recognised. It is of great importance that the service grows to provide much needed support for older people and those with dementia. The private and government sectors in South Africa are being approached to provide financial support.

During the conference project workers from Shoshanguve will be sharing their experiences.

## WHO supports World Alzheimer's Day



Dr Gro Harlem Brundtland, Director General of the World Health Organization, has formally supported World Alzheimer's Day. In her message to ADI, Dr Brundtland stresses that 'no one can ignore the problem of ageing and the increasing number of people with dementia.' Currently there are an estimated 18 million people with dementia worldwide and WHO recognises that this represents a major health problem in all countries.

The theme for this year's World Alzheimer's Day Bulletin looks at what support there is for family carers, who take the main responsibility as direct care givers. Along with the bulletin, other promotional materials include posters, postcards, badges and stickers. These are now available from the secretariat and are free of charge.

### Tax-free donations

**ADI are registering a UK charity, Friends of ADI, to enable ADI to take advantage of tax exemptions on charitable donations from UK based donors. If you would like to make a donation, please make cheques payable to 'Friends of ADI' and send it to Friends of ADI, 45/46 Lower Marsh, London, SE1 7RG.**



Alzheimer's  
Disease  
international  
15th annual  
international  
conference

For a conference announcement please contact  
Global Conferences:  
Tel: +27 21 762 8600  
Fax: +27 21 762 8606  
Email: [adi99@globalconf.co.za](mailto:adi99@globalconf.co.za)  
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or the ADI secretariat