

Global Perspective

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

Help for caregivers – online!



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Alzheimer's Disease International has recently launched 'Help for Caregivers' on its website. This part of the ADI website is dedicated to all who care for people with dementia. It can be found at www.alz.co.uk. The site has two parts:

- Information and advice provides information on how to best look after someone with dementia, offering prac-

tical and helpful advice on many daily tasks and challenges faced by caregivers. It includes subjects from bathing and eating to help in finding a nursing home.

- The Alzheimer portal where you will find contact information for national Alzheimer associations around the world. It also provides links to additional and reliable websites.

ANNOUNCEMENTS & CONFERENCES

4 April

2nd International Pharmacoeconomic Conference on Alzheimer's Disease
Stockholm, Sweden
Email: Bengt.Winblad@neurotec.ki.se

4-7 April

International Psychogeriatric Association and Royal College of Psychiatrists' Faculty of Old Age
Non-Alzheimer Cognitive Impairment
Newcastle-Upon-Tyne, UK
Tel: +44 (0) 191 256 3312
Fax: +44 (0) 191 219 5071
Email: ipaconference@ncl.ac.uk
Web: www.ncl.ac.uk/psychiatry/ipa_conference

23-25 June

World Psychiatric Association
Legal and forensic psychiatry
Madrid, Spain
Tel: +34 91 361 2600
Fax: +34 91 355 9208
Email: foresic@tilesa.es
Web: www.tilesa.es/forensic

6-8 September

International Psychogeriatric Association and the Argentine Society of GerontoNeuroPsychiatry
Mental Health in the Elderly: Transcultural Perspectives
Buenos Aires, Argentina
Tel: +1 847 784 1701
Fax: +1 847 784 1705
Email: ipa@ipa-online.org
Web: www.ipa-online.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

14-18 October

5th Congress of the European Federation of Neurological Societies
Copenhagen, Denmark
Tel: +45 4492 4492
Fax: +45 4492 5050
Email: efns@discongress.com
Web: www.weblink.pt/efns2000

19-22 November

First International Quality Research in Dementia Conference: Advances in cause, cure and care for dementia
London, UK
Tel: +44 20 8527 8408
Fax: +44 20 8527 8404
Email: enquiries@neuropsych.co.uk
Web: www.alzheimers.org.uk

PUBLICATIONS

Alzheimer's At Your Fingertips

By Harry Cayton, Dr Nori Graham and Dr James Warner. Clear and helpful answers to all your questions about Alzheimer's disease and other forms of dementia. £14.95 available from Class Publishing, London W6 7BR, UK (tel +44 1752 202301; fax: +44 1752 202333).

Managing Alzheimer's Disease in Primary Care

By Henry Brodaty. £12.95 available from Plymbridge Distributors, Estover Road, Plymouth, Devon, PL6 7PZ, UK (Tel: +44 1752 202 301; Fax: +44 1752 202 331; Email: orders@plymbridge.com. Please quote ISBN: 1-85873-312-X.

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: +44 020 7482 2202, fax: +44 020 7482 7088, email: arbl@globalnet.co.uk)



9-18 July

World Alzheimer Congress 2000: Pivotal Research and Creative Care

9-15 July **Pivotal Research** comprises the 7th International Conference on Alzheimer's Disease and Related Disorders

15-18 July **Creative Care** comprises Alzheimers Disease International's 16th Annual Conference

Washington DC, USA
Tel: +1 312 335 5813
Fax: +1 312 335 1110
Email: alzheimers2000@alz.org
Web: www.alzheimer2000.org

NEW PUBLICATION

Video: **Dementia in primary care**
ADI in collaboration with the Institute of Psychiatry at the Maudsley, London has produced a training video aimed at general practitioners which covers:

- screening for dementia
- diagnosing different dementias
- working with carers
- functional assessment and managing behavioural problems

The video is currently being translated into Spanish. Both English and Spanish versions (once completed) are available free of charge from ADI. Please contact the secretariat for your copy.



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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 CARERS STORY FROM NIGERIA

Some evenings she would head stubbornly 'on a journey'

YVONNE IHEGIHU

My maternal grandma and I were always close. As a young teenager, we became even closer as I accompanied her to the diabetic clinic. She would tell me how wonderful doctors were and how she very much wanted me to become a geriatric doctor. It was her talk more than anything else that made me interested in Alzheimer's disease.

I first noticed the signs of her deterioration when I came back from university one day (I was in my third year) and I asked her for my 500 Nigerian dollars she was looking after. She told me she could not remember having it and when I insisted, she started crying. I immediately knew something was wrong. She woke me up the next morning and gave me 680 dollars. I was quite alarmed as grandma was a local treasurer in her community and treasurers don't make such mistakes! The two nights I spent with her were very frustrating. She woke up at odd hours in the night pacing round the room and uttering inaudible words. I was so afraid and honestly thought she was either possessed or going crazy. I explained my fears to a neurologist who told me grandma had

Alzheimer's disease. My mum was so afraid that she had to move in permanently with her.

We woke up day after day to find that grandma had wet her bed and seemed to be losing touch with reality. She didn't recognise anyone at first glance except me. This frustrated her children and relations but they got used to it. It depressed me but I loved her more and prayed she would get better one day.

Three years after her first symptoms she lost most of her hearing and could not do anything without help and supervision. We had to protect her and made sure someone was always around her. My lifestyle changed because I was always at home in the village to help care for her.

Some evenings, she would pack which ever of her possessions she

could find and head stubbornly 'on a journey'. My mother would be at her wits end at such times. I would hold her hand and take her round the neighbourhood pretending to be heading in the direction of her destination and then take her back home. She never knew the difference but this made her happy. It was on one of those 'apparent journeys' alone that she tripped and fractured her right leg. Confinement to bed hastened her deterioration and caring for her became more difficult. But at this point, we were also more patient.

I had to teach my mum how to massage and turn her hourly to prevent pressure sores. At this point grandma could no longer recognise me. In November 1996 at the age of 84 years, she died after being in coma for 2 days. The Alzheimer's Association of Nigeria has become a source of warmth, encouragement and enlightenment for the family, and most especially me.

Four years later, when I attend some of my elderly patients I see her there.



The time of our lives

Age Exchange have just hosted an International festival of reminiscence in London. The festival comprised performances and workshops featuring work by both young and old to celebrate the past and present life experience of older people at this turn of the century. Groups from the UK, Germany, Austria, Russia, the Caribbean, Taiwan, Switzerland and the Netherlands participated. In addition, ADI sponsored Sandra Ferreira from South Africa to come and perform the one woman show she also wrote called *My Sad Inheritance*. The play was also staged at ADI's conference in South Africa last September.

For more information about Age Exchange write to: Age Exchange, 11 Blackheath Village, London, SE3 9LA; tel: +44 20 8318 9105; fax: +44 20 8318 0060; email: age-exchange@lewisham.gov.uk; web: www.age-exchange.org.uk

Members' Forum

ISRAEL

Congratulations to the Alzheimer's Association of Israel who have succeeded in lobbying their government to make dementia drugs available free of charge. This result comes at the end of an aggressive two year campaign headed by a parliamentary lobbyist the association hired.

Up until January 2000, drugs for people with Alzheimer's disease were only available at a cost of US\$200 per month. Once a year, a public committee decides on which new drugs will be added to the basic health 'basket' – which means they are available free of charge. This 'basket' is very limited and it is difficult to get new drugs added.

The association started their campaign by enlisting the support of the Deputy Minister of Health. A special committee was formed with the Deputy Minister's board and the association's scientific and medical board. This committee recommended that drugs for people with Alzheimer's disease be added to this basket. However, this recommendation was rejected by the Minister of Health.

The following year, the Deputy Minister of Health was appointed Minister, and the association reminded him of his previous recommendations! The association then launched their campaign in parliament, repeatedly highlighting the issue on television and in the newspapers. Volunteers telephoned and faxed the Ministry of Health every day begging him to give his support. The scientific committee prepared position papers on the drugs, and these were circulated amongst public committees and the media. In the end the association won the battle as the Minister

kept his promise and added these drugs to the 'basket'.

This campaign has not only made these drugs available free of charge, it has also raised the profile of the association tremendously. The Alzheimer Association of Israel has now become one of Israel's most important and powerful lobbyist organisations.

NETHERLANDS



Farewell and good luck to Harry Crielars, who left the Alzheimer's association Alzheimer-stichting last October to join Greenpeace Netherlands.

GREECE

The Greek Society of AD and Related Disorders hosted the first Panhellenic conference during January. The meeting was a great success and brought over 500 participants together in Thessaloniki. Workshops were run on organisational issues to strengthen the work of Alzheimer associations. These were reinforced by presentations made by Elizabeth Rimmer, executive director of ADI, and Nori Graham, chairman of ADI.

AUSTRALIA

Congratulations are also in order to Henry Brodaty, vice chairman of ADI. Henry was awarded an Order of Australia for service to the health and well-being of older people in the community as a leader in dementia care through the Alzheimer's Association, both nationally and internationally, and to medicine through contributions to the speciality of old age psychiatry and academic and research knowledge in psychogeriatrics.



EGYPT

Egypt has been tackling the problems associated with an ageing population since 1982 when Cairo hosted an international conference for Mental Health of the Elderly.

Professor Ashour, chairman of the Egyptian Alzheimer Group, first made contact with ADI in 1984 through postal correspondence, attending some ADI conferences and visiting chapters in the US and Australia. However, it was not until he met Nori Graham, chairman of ADI, at a meeting in Lebanon in 1998 that practical steps to initiate an Alzheimer's group were taken.

Of the estimated 61 million people in Egypt, approximately 100,000 people have some form of dementia (5.1% of the population are 60 years of age and over). Most of the formal health and social services in Egypt are geared towards a young population, with priority given to primary and emergency care. There are few non governmental organisations working with caring for the elderly or with development. In Egypt, it is the family who traditionally care for the elderly alone or with limited resources.

Since making contact with ADI, the Egyptian Alzheimer Group have benefited from the opportunity to find out about experiences in other countries as well as strengthen the running of their organisation. Egypt was one of the participants of the Alzheimer University in 1999. The group are now concentrating on activities such as :

- Raising awareness through national campaigns
- Setting up memory clinics (these have been linked in with the psychiatric or geriatric clinics and focus on training, education, research and support). So far there are 5 memory clinics
- Starting support groups for carers

EMERGING ALZHEIMER ASSOCIATIONS



Participants at the first meeting for caregivers in Peru

PERU

The Peruvian Association of Alzheimer Disease and Other Dementias (APEAD) officially registered as a charity in January 2000. The group actually started some months ago with family and professional support and enthusiasm! APEAD comprises family members, caregivers, medical doctors, other professionals and members of the community. And all have something in common: they want to help and improve the lifestyle of people with dementia and those who care for them.

The main purposes of APEAD are to:

- provide accurate information about AD
- set up social activities
- give support and help to caregivers and people with dementia
- start support groups
- encourage research
- establish care standards
- promote the creation of day care centers

The First Forum for Caregivers and Family Members of people with Alzheimer's disease was held in Lima, Peru, in December. It was sponsored by Mr Datorre and Mrs Noemi LaHoz, both from the Peruvian Alzheimer Foundation of Miami (which is currently being set up). The meeting was a great success, concluding with participants realising the necessity for a Peruvian Alzheimer Association.

CYPRUS

The Pancyprian Association of Alzheimer's Disease was formed on 17 January 1996. The association is based in Larnaca, but already has a branch in Nicosia and are in the process of establishing one in Limassol. The group raise awareness throughout Cyprus by distributing leaflets, publishing articles in newspapers and giving interviews on local radio. They also organise a Pancyprian conference every two years bringing together their members and professionals.



Hussain Jaffri, founder of the Alzheimer's association in Pakistan

PAKISTAN

Six years ago, Hussain Jaffri noticed his grandfather's odd behaviour and consulted several doctors until Alzheimer's disease was finally diagnosed – a disease he had never heard of. Once the diagnosis had been made, no one had anything to offer except telling him the prognosis. Hussain went from pillar to post asking for any sort of information and it was at that point that he contacted ADI for help. Getting as much literature and information as he could not only gave him a new look into the disease but it was heartening to know that there were many other people like him in the world who were looking after people they loved who had dementia. Sharing their experience ended the feeling of loneliness that he had.

It was also at that time that he took up a mission that a similar society should be created in Pakistan which could help people who were as desperate as he was. Today Hussain is happy that he has accomplished his goal. He now works with a group of volunteers (who also have a family member with dementia), doctors, clinical psychologists and social workers, who all got together to establish Alzheimer's Pakistan.



World Alzheimer's Day street campaign in Kobe, Japan

World 21 September Alzheimer's Day

ADI is currently putting together materials for this year's World Alzheimer's Day. The focus of the bulletin will be on quality of life and what that means to people with dementia and their carers. Posters, post-cards, stickers, badges and bookmarks will be available.

If you would like to organise an event to celebrate World Alzheimer's Day, or simply put a display up in your hospital, shop, library, etc why not order some materials. These are available free of charge.

Please fill in the order form below specifying quantities required and return to ADI by 30 April at: 45/46 Lower Marsh, London, SE1 7RG. (Tel +44 20 7620 3011; fax: +44 20 7401 7351; email: adi@alz.co.uk)

Please send the following for World Alzheimer's Day:

<p>QUANTITY</p> <input type="text"/> Bulletins (English) <input type="text"/> Bulletins (Spanish) <input type="text"/> Postcards <input type="text"/> Stickers	<p>QUANTITY</p> <input type="text"/> Posters <input type="text"/> Badges <input type="text"/> Bookmarks
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Name _____

Organisation _____

Address _____

Galantamine receives first European Union approval

Galantamine (Reminyl®), a new symptomatic treatment for Alzheimer's disease developed by Janssen-Cilag, received its first regulatory approval within the European Union from Sweden. Galantamine will subsequently be submitted through the EU Mutual Recognition Procedure to gain marketing approval in Europe.

Submissions have also been made to the authorities in Canada, Australia, Switzerland, Poland, South Africa and New Zealand during the second quarter of 1999 and to the US Food and Drug Administration (FDA) at the end of September 1999.

Become an associate member of Alzheimer's Disease International

Individuals and organisations can become associate members and receive the newsletter and notice of events and publications

I wish to become an associate member of Alzheimer's Disease International

Name _____

Address _____

I enclose payment of

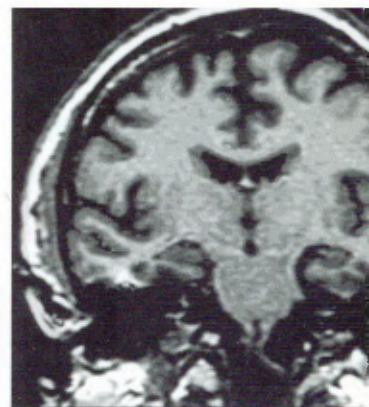
- £10/\$15 or
- a donation of £/\$

Payment can be made by UK cheque or banker's draft in either US dollars or Sterling, to Alzheimer's Disease International, 45/46 Lower Marsh, London SE1 7RG

An expanded research project in the UK

Quality Research in Dementia

DR RICHARD HARVEY
DIRECTOR OF RESEARCH
ALZHEIMER'S SOCIETY (UK)



The Alzheimer's Society in the UK has been funding research since the early 1990s. Projects funded range from basic science investigations into the processes inside the nerve cell in Alzheimer's disease, to carer support and psychosocial interventions. The Alzheimer's Society re-launched its expanded research programme as Quality Research in Dementia (QRD) in July 1999.

Research is one of the five key activities of the Alzheimer's Society. The Society views supporting research as a sustained and long term process – ultimately it will be the way to defeat the diseases that cause dementia.

QRD has two main aims:

1 To encourage researchers in the UK to apply for grants. As well as continuing fellowship grants, QRD now funds research projects headed by more senior researchers, and innovation grants that encourage significant breakthroughs to occur.

2 To involve people with dementia and their carers in all aspects of the research programme. Up until now, the decision on what research is to be a priority, and who is to be given research grants has been made by scientists and researchers alone. However, there is a growing consensus that partnership between scientists, doctors and lay people may actually lead to better research. It may also ensure that people with dementia and their carers see the research results much earlier.

QRD has an Advisory Network of carers and people with dementia who want to be directly involved in the programme. Members of the Advisory Network provide help by:

- Commenting on research grant applications
- Helping decide which research should be funded
- Getting involved in research in their local area

- Helping to prioritise topics for funding
- Telling QRD what they think about the research being funded
- Getting the research results into practice in their local area

Members attend two one-day workshops that provide research skills and empowerment training. The Network currently has more than 100 volunteers, many of whom have now participated in the research programme.

Through QRD, the Alzheimer's Society is making a significant commitment to understanding the causes of dementia, finding cures, and delivering evidence for the most effective care practices for people with dementia and their carers. For more information contact: Quality Research in Dementia, Institute of Neurology, Queen Square, London WC1N 3BG. Web: www.alzheimers.org.uk (follow the link to 'Quality Research').



Essential reading for all those working with people with dementia

The **Journal of Dementia Care** is published six times a year. For a free sample copy and subscription details, please send your name and address to **The Journal of Dementia Care, HAWKER Publications, 13 Park House, 140 Battersea Park Road, London SW11 4NB**. Fax: +44 20 7720 2108

Focus on

The Alzheimer's Association

Founded in 1980, the Alzheimer's Association USA (host of this year's ADI conference) works through a network of over 200 chapters across the US, providing support and information to the estimated 4 million Americans who have Alzheimer's disease and their families.

A key issue for the association is advocating for improved public policy and promoting legislative priorities. This is undertaken at the public policy office, conveniently located on Congress's doorstep in Washington DC.

The association has conducted research which indicates that Alzheimer's disease costs American businesses more than \$33 billion a year: \$26 billion is attributed to lost productivity of carers; whilst \$7 billion is related to costs for health and long-term care.

The association has already made the largest ever private investment in Alzheimer research through the Ronald and Nancy Reagan Institute. They are also generating new models of care through other initiatives, programs and publications.

The Alzheimer's Association is now calling on Congress and the President to match their private commitment with federal government resources by:

- Increasing funds by \$100 million
- Redesigning the healthcare system
- Providing protection against the financial burden of long term care



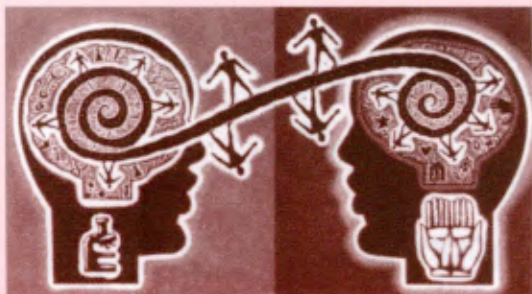
PHOTO © DANIEL J SPLAINE, FLUM ISLAND PHOTOGRAPHICS

The Reverend Jesse Jackson making the keynote address to the 1999 Public Policy Forum in Washington DC, USA

Research by the association shows that currently more than 7 out of 10 people with Alzheimer's disease in the US live at home. Almost 75% of the home care is provided by family and friends. The remainder is 'paid' care, costing an average of \$12,500 per year – most of which is covered by families.

Alzheimer's Association, 919 N Michigan Avenue, Suite 1000, Chicago, Illinois 60611, United States of America. Fax: +1 312 335 1110. Web: www.alz.org

World Alzheimer Congress 2000



With Change in Mind

Pivotal Research and Creative Care

Leaders in Alzheimer's research and care from around the world will come together in Washington DC to learn and share from one another, during the World Alzheimer Congress 2000, July 9-18 2000.

The congress comprises the following events:

- **Pivotal Research:** July 9-13
- **Bridging Research and Care:** July 13-14
- **Creative Care:** July 15-18

Creative Care is made up of the 16th Alzheimer's Disease International Conference, the 9th Alzheimer's Association (USA)

national education conference and the 22nd annual conference of the Alzheimer Society of Canada.

Throughout the programme key themes will reinforce and illustrate creative care. These themes include recognising the global impact of dementia, translating research into practice, addressing needs of younger people with dementia and their families, understanding systems of care, supporting the workforce and reaching diverse populations.

Please visit the conference website for more information and registration details: www.alzheimer2000.org