



Global Perspective

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

ADI goes to Africa

ADI's 15th annual international conference was held in Johannesburg, South Africa, 15-18 September 1999

REPORT BY DR AJIT SHAH, CONSULTANT PSYCHIATRIST UK

This excellent international meeting was attended by over 800 delegates from 49 countries. About 350 came from the host country.

Delegates included professionals from almost all disciplines associated with dementia and family carers. The meeting offered something for everyone with high quality presentations and workshops on a wide range of topics. Sessions were very well attended with a great deal of interaction between speakers and audience. The two 'meet the experts - question and answer' sessions were very well received.

Several sessions addressed various aspects of dementia in developing countries. Data from pioneering work in Cuba, South Africa, East Africa, Nigeria and China were presented. These reinforced the importance of dementia in an ageing population - a message conveyed by all plenary

speakers. These sessions also highlighted the need for cross-cultural research not only to help plan services but also to identify the causes of dementia.

An important session was on non-cognitive features of dementia and their treatments viewed from several perspectives. A new anti-Alzheimer's disease drug Galanthamine was reported to improve cognitive features and some non-cognitive features - the latter having important implications for care of all people with dementia.

Some sessions concentrated on biological aspects of dementia including genetics and neuroimaging. This field seems to be moving rapidly and such updates on the current 'state of the art' were very well received.

Excellent models of innovative community services were also reported from several countries. These reminded us all what can be done and encouraged us to have enthusiasm. Presentations on various aspects of carer involvement in dementia and on issues such as advocacy and competence were also given.

An afternoon was dedicated to the ADI 10/66 dementia research group chaired by Dr Martin Prince from London. The group was updated on the progress of the proposed collaborative research projects from four regions (India



Hennie de Clerq (Chairman ARDA), Kathy Beukes (Executive Director ARDA), Adelaide Tambo and Nori Graham (Chairman ADI) at the conference

and Sri Lanka, Africa, Latin America and the Caribbean, and China and South East Asia). This meeting served to bring together many researchers from different parts of the world and develop a common forum for local and cross-cultural research in a collaborative manner that has not been possible before.

Many of the above topics were also addressed in the excellent poster presentations.

All participants enjoyed this meeting. It was a great success and the organisers should be congratulated. It also allowed an opportunity to meet old friends and make new friends. There was a family atmosphere. We now look forward to the next conference in Washington DC, 15-18 July 2000.

IN THIS ISSUE

- Announcements 2
- Report: Vascular Dementia. 2
- From the heart: Trinidad and Tobago 3
- Members' Forum 4-5
- The Nun Study 6
- Video for training GPs 6
- Charter of Principles 7
- Spirit of ubuntu 8

ANNOUNCEMENTS

1999

2-4 December 1999

Rehabilitation Engineering Research Center on Aging*Promoting independence and quality of life for older persons*Virginia
USA

Tel: +1 716 829 3141

Fax: +1 716 829 3217

Email: swilson@acsu.buffalo.edu

Web: www.wings.buffalo.edu/ot/cat/conference

2000

29-31 March

3rd Latin American and Caribbean Regional MeetingHavana
Cuba

Tel: +53 7 552 164 extn 1514

Fax: + 53 7 228 382

Email: zosima@paclco.get.cma.net

4 April

2nd International Pharmacoeconomic Conference on Alzheimer's Disease

Stockholm, Sweden

Web: www.siumed.edu/cme

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

5-8 April

6th International Stockholm Springfield Symposium*Advances in Alzheimer Therapy*

Stockholm, Sweden

Web: www.siumed.edu/cme

10-13 May

Middlesex University Health Research Centre*Alzheimer's Disease: Getting a Clearer Picture*

London, UK

Tel/fax: +44 20 8362 5558

Email: C.Sykes@mdx.ac.uk

Web: www.mdx.ac.uk/www/jhp/ecad.htm

23-25 June

World Psychiatric Association*Legal and Forensic Psychiatry*

Madrid, Spain

Tel: +24 91 361 2600

Fax: +34 91 355 9208

Email: forensic@tileasa.es

Web: www.tileasa.es/forensic

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 Alzheimers Disease International's 16th

Annual Conference

Washington, USA

Tel: +1 312 335 5813

Fax: +1 312 335 1110

Email: alzheimers2000@alz.org

Web: www.alzheimer2000.org

6-8 September

International Psychogeriatric Association and the Argentine Society of GerontoNeuro-Psychiatry*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

REPORT

First International Congress on Vascular Dementia

The first International Congress on Vascular Dementia was held in Geneva, Switzerland, October 3-6 1999. Although the importance of vascular disease and the brain's blood supply have been recognised since the early days when dementia was first described, this conference was a 'first'. The pace of research in this area has accelerated considerably over the last few years. It is increasingly recognised that diseases such as hypertension and diabetes, which affect the blood vessels and blood supply to the brain, are not only risk factors for dementia due to repeated strokes but also for Alzheimer's disease. These findings in community studies are paralleled by progress in identifying vascular damage both in life through advances in brain scan technology, and after death through postmortem research.

A special session was devoted to the life and work of the late Luigi Amaducci who contributed so extensively to the understanding of dementia as well as to ADI. The first prize to be set up in his honour was awarded to Professor Elaine Perry for outstanding achievement in research into dementia.

PUBLICATIONS

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, UK

Tel: +44 20 7482 2202

Fax: +44 20 7482 7088

Email: arbl@globalnet.co.uk

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, UK

Tel: +44 20 7482 2202

Fax: +44 20 7482 7088

Email: arbl@globalnet.co.uk

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

Tax: +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 202301

Fax: +44 1752 202331

Email: orders@plymbridge.com.

Quote ISBN: 1-85873-312-X



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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 carer's story from Trinidad and Tobago

'I miss her touch and her gentle hug most'



Irma Johnson, Tessa Gopaul's mother

My mother has had the disease for over 14 years – she was 65 when it started. She lived with me for seven years and is at present living with my brother and his family.

In the early stages, mummy was repetitive: she forgot simple things like the date, month, day. Not having a clue about the disease, I would very often get impatient with her. She also knew that she had a problem – at first she would laugh at herself and one day admitted that she was doing silly things and that she was confused and afraid.

The seven years that she lived with me were probably the most frustrating and guilt filled years of my life, but they were also years when my love for her deepened and my commitment to her became stronger as the roles were reversed and it was my turn to look after her.

The time came when she could no longer take care of herself nor do most things that we take for granted in our every day lives. We had to protect her in and around the home and ensure that she did not get hurt or wander and get lost. She never sat still and paced constantly which I think was what made me the most angry and frustrated, as she needed constant supervision.

Patience was not one of my virtues, and many times during that period I had to take time out and take control of myself. I found

myself looking up to the heavens and asking the Lord 'how much longer' before carrying on. As a result, I sometimes vented my frustrations on those closest to me – in other words I felt trapped.

As the disease progressed I became aware of the different stages and became more observant – eventually I was able to anticipate her moods and on entering the house I would immediately know whether or not she had had a good day.

The emotional stress of care giving can cause depression, embarrassment, tension, anger, guilt, loss of self-esteem and a feeling of being overwhelmed. You also grieve for your loved one – the loss of personality, of human intellect – of everything that makes a person a person. The entire family is affected when you are taking care of an Alzheimer's patient because your lifestyle changes.

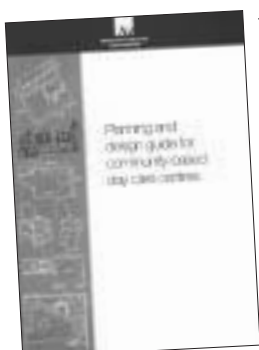
Many caregivers feel that others do not understand (and many times, they do not) or that their feelings are unacceptable. The most important thing a caregiver can do is to recognise his or her needs – remember you are important. Our friends and family also need to be educated about the disease so that they can help us to cope. You must be able to walk away without feeling guilty.

Mummy is now in the final stages of the disease. She still senses my

presence when I visit her and responds to my voice with her gentle smile. She is no longer able to walk and just sits still and stares blankly into space. I on the other hand am still trying to deal with my own grief – because what I miss most is her touch and her gentle hug.

We must remember that the person with Alzheimer's responds to a touch, a hug, a hand held, a kiss, a gentle stroke. All this would help your loved one to know that you are there for them and that you are prepared to take care of them and love them – the best way that you can.

TESSA GOPAUL



New publication

Planning and design guide for community-based day care centres

This design guide sets out the principles for the provision of day care centres. If you would like a copy, contact the Secretariat.

Members' Forum

ADI NOW HAS 50 MEMBERS

Congratulations and welcome to the following countries who were formally accepted as ADI members at the Annual General Meeting in Johannesburg during September: Iceland, Malaysia, Nigeria, Russia, Slovak Republic, Thailand, and Uganda.

SCOTLAND



Alzheimer Scotland – Action on Dementia has recently released the research report 'The Quality Challenge: Caring for people with dementia in residential institutions in Europe'. The report was produced

in partnership with counterpart associations in the Netherlands, Italy and Spain. It explores comparisons between European countries' provisions and quality of residential institutional care for people with dementia, a policy field which has received little attention. For more information please contact Alzheimer Scotland – Action on Dementia at: 22 Drumsheugh Gardens, Edinburgh EH3 7RN, UK; tel: +44 131 243 1453; fax: +44 131 243 1450; email: alzheimerscot.org

INDIA

Scott Watson and Louise Ashmore are both care workers from Glasgow with experience of working in residential homes and specialised dementia units for older people in the UK. When asked why they wanted to do voluntary work in India, three particular reasons stood out: the scale of the global challenge as highlighted by ADI's World Alzheimer's Day bulletins; their understanding of the need for an increased support and care services; and a strong belief in their own abilities. ADI encouraged and supported their proposal and

both Alzheimer Scotland – Action on Dementia and Dementia Services Scotland took time to lend a hand.

Scott and Louise were made to feel at home by ARDSI staff the moment they arrived in Cochin. After two months they had an understanding of the range of services provided by ARDSI and an appreciation of the enormous task of raising public awareness across the Indian sub-continent. During this time they also attended several conferences, highlighting the rapidly growing population over 65 years of age in India. These conferences evoked very mixed emotions and they found that delegates, mainly doctors, were aware of the health issues relating to dementia but lacked an understanding of the social and economic consequences.

Scott and Louise have undertaken specific tasks within ARDSI and the Urban Community Dementia Services in Cochin, with the aim of strengthening and developing the work of ARDSI. They are using their experience to design training sessions for the community geriatric nurses and student nurses. Louise is also liaising with the chapters of ARDSI throughout India to develop a stronger network.

USA

The wife of a person with Alzheimer's disease who died in 1998 has formed an Alzheimer's support group designed specifically for children after watching how her husband's illness affected their grandchildren. The group, open to children aged 6-14, will hold its first session later this autumn in Oregon, USA.

The meetings are intended to help the children understand the disease and cope with their feelings about it. Children will share photos and talk about the relative, and make a 'memory book' dedicated to them.

THE GLOBAL WALKATHON

The biggest health promotion event in history by and for older people took place on Saturday 2 October 1999 in more than 1500 cities in 86 countries. Over two million people of all ages staged a global 'walkathon'

to support the concept of 'active ageing' – the World Health Organization's (WHO) response to the rapidly growing number of men and women over 60 in the world. The worldwide walk, known as the Global Embrace, also celebrates the United Nations 1999 International Year of Older Persons.

Dr Alex Kalache, head of WHO's Ageing and Health Programme says 'the thinking behind the Global Embrace is quite simple. Informed changes in life style and sensible public policies – not miracle drugs – are the road to active ageing'.

Several ADI members also participated in the Global Embrace including the Alzheimer's and Related Disorders Society of India (ARDSI). Over 1500 people walked the streets of Cochin. The walk was preceded by a seminar and was followed by several cultural programmes. The whole day was given extensive media coverage. The Trivandrum Chapter of ARDSI also organised a walkathon.

The Greek Association of Alzheimer's Disease and Related Disorders joined forces with several other organisations, encouraging the surrounding ten towns around Thessaloniki to join in the Global Embrace.

IRELAND



ADI is sad to announce the recent death of Michael Coote. Michael had many friends within ADI through his involvement on the ADI and Alzheimer Europe boards and as president of the Alzheimer's Society of Ireland. He will be sadly missed.

REGIONAL MEETING

Singapore, September 1999

The Alzheimer's Disease Association of Singapore hosted the second Asia Pacific regional conference in September. Delegates from Australia, Hong Kong, India, Indonesia, Japan, Malaysia, New Zealand, Philippines, Sri Lanka, Taiwan, Thailand and Singapore met over two days and were rewarded with stimulating discussions, a fostering of friendships and developing networks. For those countries who do not have associations, healthcare professionals interested in dementia were invited to attend.

Dr Jacob Roy, Vice Chairman of ADI, gave an overview of the challenge of dementia for the region, highlighting the need for a multi-faceted approach to



developing dementia services. Other presentations included the need to establish an underlying philosophy of care as a foundation for the implementation of programmes, an overview of how some innovative services have been developed in Hong Kong, and a look at a practical hands-

on approach to managing dementia.

Delegates agreed that members would continue to work together and encourage one another, as well as meet annually to monitor the progress of dementia action in the Asia-Pacific region.

WORLD ALZHEIMER'S DAY 1999

This year's World Alzheimer's Day was a truly global celebration as over 22,000 bulletins (English), 37,000 bulletins (Spanish), 38,000 postcards, 21,000 posters and 24,000 badges were distributed throughout the world.

In Japan, over 6000 people participated in 30 lectures around the country and street leafleting campaigns were organised in 95 cities. The Trivandrum Chapter of ARDSI, India, jointly organised a public awareness programme with a local welfare organisation for women. Speakers addressed the role of the media in creating public

awareness, symptoms and various stages of brain related disorders, and the need for the destigmatisation of dementia and for compassion. Family caregivers in Nigeria arranged home visits to people with dementia and offered them token gifts. AMAES, in collaboration with Mexico City's government, organised a meeting in which 400 people attended. A video was shown and was followed by a session of questions and answers.

The Alzheimer's Society Cheltenham and District Branch, UK, held a service attended by Nori Graham, chairman of ADI. Candles were lit to represent carers, people with dementia, those involved in the caring profession and voluntary

organisations, and in remembrance. Afterwards, the year long Millennium Project to create a wall-hanging entitled 'A celebration of memories' was launched. Workshops will be organised in the region throughout the year, giving people the opportunity to see different art techniques, 'have a go', or just watch and enjoy.

Ireland launched their website, Malaysia organised a family day, Scotland celebrated with a tea day, Germany arranged a press conference and Korea held two seminars.

Why not let the Secretariat know how you celebrated World Alzheimer's Day? ADI would appreciate any photos you can send in (but please note that we are unable to return these).

Some activities in Turkey for World Alzheimer's Day 1999



Why are Nuns donating their brains to research?

The Nun Study is a longitudinal study of ageing and Alzheimer's disease. It began in 1986 as a pilot study using data collected from the Older School Sisters of Notre Dame living in Minnesota, USA. In 1990, the Nun Study was expanded to include older Notre Dames sisters living in the midwestern, eastern and southern regions of US. The study aims to determine the causes and prevention of Alzheimer's disease, other brain diseases and the mental and physical disability associated with old age.

The Nun Study is funded by the National Institute on Aging (one of the institutes within the National Institute of Health) of the United States. So far over two million of federal tax dollars have been invested in the study. The study is an ongoing one-of-its-kind resource for the study of the brain diseases in the elderly.

The primary research question in the study is 'What factors in early, mid and late life increase the risk of Alzheimer's disease and other brain diseases?'

Participants in the study are American Roman Catholic nuns. When the study began in 1986, there were 678 participants aged between 75 and 103 years, the average age being 85. Over 85% of the participants were teachers.

Each of the 678 sisters agreed to participate in annual assessments of their cognitive and physical function, medical exams, blood tests for genetic

and nutritional studies, and brain donation at death for neuropathologic studies. The Nun Study represents the largest brain donor population in the world. In addition, the sisters have given investigators full access to their convent and medical records.

The convent archives are particularly useful as they contain accurate risk factor data spanning the entire life of the participants. Accurate information on early and mid-life risk factors is difficult or impossible to obtain in most other studies on Alzheimer's disease, since individuals with the disease cannot accurately recall their history. The archives contain a wealth of information including birth certificates, socio-economic characteristics of the family, education documentation, autobiographies written in early, mid and late life, as well as residential, social, and occu-

pational data describing their mid and late lives.

Although extrapolation of findings from this unique population may be limited, this potential disadvantage is largely offset by other advantages such as the convent archives. Many factors that confound (or confuse) the findings of other studies are either eliminated or minimised because of the relatively homogenous adult lifestyles and environments of these women. Participants in this study are non-smokers, drink little if any alcohol, have the same marital status and reproductive history, have lived in similar housing, held similar jobs, and had similar access to preventive and medical care.

During the last 150 years, education has been the primary mission of the School Sisters of Notre Dame. Most sisters enrolled in the Nun Study because they believed their participation would help other women throughout the world. The findings so far would indicate that traits in early, mid and late life have a relationship with the risk of developing Alzheimer's disease, as well as the mental and cognitive disabilities of old age.

The Nun Study is directed by Dr David Snowden at the University of Kentucky. For more information on the study visit the website www.coa.uky.edu/nunnet

New video for training GPs

The main, and sometimes only, health care provided for the majority of people with Alzheimer's disease (AD) comes from primary care doctors or general practitioners. GPs work with a problem-orientated approach to medicine – seeking soluble problems and instigating appropriate management. But what if a problem seems insoluble or, worse, is not even recognised in the first place? Then the whole system brakes and care is slowed as a result. Problems are not solved, appropriate management may not be introduced and patients are not referred to secondary, specialist, care.

With this in mind a team of two psychiatrists and two GPs from the Institute of Psychiatry, UK set out to make a training video to enhance knowledge and skills in this area. The

group wanted to produce something that was going to be used and not filed in some remote corner of the surgery.

The first step was to generate a teaching module that met what the group perceived were the needs of GPs. This was used to test a group of GPs knowledge and skills of dementia using a specially developed questionnaire, followed by the module given as a lecture. Comments were collected at the end and the questionnaire repeated. Alterations were made to the teaching package based upon these comments and the results and repeated to a different group of GPs. Brief vignettes of patients and GPs were also incorporated so as to illustrate the point being made. This cycle of evaluation was repeated three

times, each time altering the package to fit in with the GPs needs. Each change in the programme was designed to accentuate those parts that had the most effect on improving skills and knowledge.

The final product was translated to video format and covers screening for dementia, diagnosing different dementias, working with carers, functional assessment and managing behavioural problems. The results of the GPs' assessments showed that the video improved skills and knowledge of AD and that this improvement was sustained at follow up three months later.

SIMON LOVESTONE
INSTITUTE OF PSYCHIATRY, UK

ADI has sponsored the video and hopes that it will be used widely. A Spanish version will be available soon. If you would like a copy, contact the Secretariat.

Charter of principles

For the care of people with dementia and their carers

ADI's charter of principles for the care of people with dementia and their carers has just been launched.

In 1998 during the ADI meeting in Cochin, India, a decision was made to develop an international charter for the care of people with dementia and their carers. A working party of ADI members, led by Verna Schofield of New Zealand, produced a draft document for consideration by all ADI members. Many members responded. The working group revised the charter incorporating the comments received and presented the final version to the ADI council for approval in September 1999 during the ADI conference in Johannesburg.

The main criteria used in developing the charter were the importance of the principles, their applicability around the world, and conciseness of presentation. The principles are all considered important - the numbering beside each principle being there to help identification, not as a ranking. An effort has been made to keep wording simple so that the document is easy to read and translate.

The charter is a working document and will be reviewed periodically. Members of ADI are able to use the charter as it stands or as a starting point for developing one of their own. If you would like to receive a copy of the charter, please contact the secretariat.

Statement of principles

Alzheimer's Disease International recognises the following principles as fundamental to the provision of care for people with dementia and for the support of their family members and carers:

- 1** Alzheimer's disease and related dementias are progressive, incapacitating diseases of the brain that have a profound impact on persons with dementia and members of their families.
- 2** A person with dementia continues to be a person of worth and dignity, and deserving the same respect as any other human being.
- 3** People with dementia need a physically safe living environment and protection from exploitation and abuse of person and property.
- 4** People with dementia require information and access to coordinated medical and welfare services. Anyone thought to have the disease needs medical assessment and those with the disease require ongoing care and treatment.
- 5** People with dementia should as far as possible participate in decisions affecting their daily lives and future care.
- 6** The family carers of a person with dementia should have their needs relating to the care assessed and provided for and should be enabled to take an active role in this process.
- 7** Adequate resources should be available and promoted to support people with dementia and their carers throughout the course of the disease.
- 8** Information, education and training on the disease, its effects and how to provide care must be available to all those involved in the assistance of people with dementia.

Alzheimer's Disease International Conference, Johannesburg 1999

The spirit of ubuntu

Ubuntu: an African concept meaning sharing the pot, offering a helping hand



“My courage as a carer was based on lack of knowledge”

“Granny may be the breadwinner. She may have a pension of R50 – and five or six unemployed people depend on her”

“I thought about going to the workshop on managing conflict in your organisation, until I saw it was run by someone in MY organisation”

*“Without my memories I would never have survived”
(Nelson Mandela)*

- 1 Nori Graham, Chairman ADI
Henry Brodaty, Vice Chairman ADI
Orien Reid, Chairman Alzheimer's Association, USA
- 2 Susan Frade (RIGHT), ADI secretariat, distributing ADI literature
- 3 The local witch doctor
- 4 One of the many successful workshops
- 5 The exhibitions marquee was a place for eating and meeting
- 6 Enjoying the social life
- 7 Verna Schofield, ADI Executive, Ian McColl, Alzheimer Society of New Zealand National Executive member, and Wendy Fleming, Chairman of ADI Conference 2001

“The best pill people with dementia have is their family”

“Your presence is a statement of hope that we will meet the challenge of dementia”

“Hang on to the ubuntu”