World Alzheimer Congress 2000

World experts meet in Washington to share global dementia strategies

Over 5000 world leaders in dementia research and care united in Washington, D.C. in July for World Alzheimer Congress (WAC) 2000, the largest dementia research, education and networking event ever held. The aim of the 10-day meeting was to share information on research and care, help identify strategies for improving the lives of people affected by dementia and meet the challenge dementia poses to us today and in the future. This unique gathering of scientists, healthcare professionals, caregivers and staff and volunteers of Alzheimer associations was the collaborative effort of Alzheimer's Disease International, Alzheimer's Association (USA) and the Alzheimer Society of Canada.

WHO ANNOUNCEMENT

World Health Day 2001 will focus on mental health

The year 2001 will offer a historical opportunity to highlight the importance of mental health in the world. The Director General of WHO has selected mental health as the theme of World Health Day, to be observed, as in every year, on April 7. The selection of the theme comes in recognition of the impact of mental disorders, including Alzheimer's disease and other dementias and of the fact that despite growing knowledge, little of this knowledge benefits the populations most affected. Governments have yet to face the challenge and society has to do much more in the way of reducing stigma and discrimination. We all know that support for people with dementia and their carers needs to be expanded.

World Health Day will be followed by the annual World Health Assembly in May which brings together all the health ministers of the world. ADI has been invited to participate in the Assembly by organising a stand at the Palais de Nations, where the event takes place. We are also requesting an opportunity to address the Assembly on the global impact of dementia.

In June 2001, the World Health Report will be launched. This scientific publication released by the Director General of WHO will contain the most up-to-date information in the field of mental health – including dementia, advocacy information for expansion of services, improved policies and promotion of research. ADI is assisting WHO with the preparation of the dementia component of this report.

ADI will join WHO in observing World Health Day and turning it into a major success. We have promised WHO to be at their side and support its efforts.

IN THIS ISSUE

Announcements . . . . . . . . . . . . . . 2
Living with dementia . . . . . . . . . . . . 3
Members' Forum. . . . . . . . . . . . . . . 4-5
Emerging association: Croatia . . . . 6
Spotlight on Malaysia. . . . . . . . . . . . 6
World Alzheimer's Day . . . . . . . . . . . 7
Exercise and dementia . . . . . . . . . . . 8-9
World Alzheimer's Congress . . . . . . 10-12
ANNOUNCEMENTS & CONFERENCES

4-6 October
European Association of Homes and Services for the Ageing
Ageing in Europe in the New Millennium
Maastricht, Netherlands
Tel: +31 43 361 91 92
Fax: +31 43 361 90 20

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
Web: www.eurokongress.de

13-15 October
International Psychogeriatric Association and the Brazilian Society of Geriatric NeuroPsychiatry
Mental Health in the Elderly: Transcultural Perspectives
Porto Alegre, Brazil
Tel: +1 847 784 1701
Fax: +1 847 784 1705
Email: ipa@ipa-online.org
Web: www.ipa-online.org

14-18 October
5th Congress of the European Federation of Neurological Societies
Copenhagen, Denmark
Tel: +45 4492 4492
Fax: +45 4492 5050
Email: efnfs@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 8362 5735; fax: +44 20 8362 5736;
Email: enquiries@neuropsych.co.uk
Web: www.ipa2001@nice-acropolis.com

25-27 October 2001
17th Alzheimer’s Disease International Conference
Partnerships in Dementia Care
Christchurch, New Zealand
Tel: +64 3 364 2534
Fax: +64 3 364 2057
Email: alz@cont.canterbury.ac.nz
Web: www.conference.canterbury.ac.nz/alzheimer2001

PUBLICATIONS

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 20 7482 2202, fax: +44 20 7482 7088, email: arbl@globalnet.co.uk)

Alzheimer’s Disease in Primary Care Second Edition
By Serge Gauthier
£65 available from Martin Dunitz Publishers,
The Livery House, 7-9 Pratt Street, London
NW1 0AE (Tel: +44 20 7482 2202, fax: +44 20 7482 7088, email: arbl@globalnet.co.uk)

Dealing with Dementia: Recent European Research
By David Marks and Catherine Sykes
£15.99 available from Middlesex University Press,

Clinical Diagnosis and Management of Alzheimer’s Disease Second Edition
By Serge Gauthier
£9.95 available from Martin Dunitz Publishers,
The Livery House, 7-9 Pratt Street, London
NW1 0AE (Tel: +44 20 7482 2202, fax: +44 20 7482 7088, email: arbl@globalnet.co.uk)

Advertising

ANNOUNCEMENTS & CONFERENCES

1-85873-312-X
What it’s like to live with Alzheimer’s

BY SHELIA, A WOMAN WITH EARLY-STAGE ALZHEIMER’S DISEASE

I am getting along just fine and a lot of the time I don’t think about my memory problem. Now, having written that, I will write about what does bother me...

I t bothers me that I asked my daughter if she would take the clothes home with her to put them in her dryer. She didn’t make any remark, but after she left I realised that I have my own dryer that I have been using for the past three years.

I decided to put up a little shelf on the wall in my room. I bought my tool box out and opened it. I scrounged around for nails and my small hammer. There in the box were my crystal decanter stoppers rattling around with the heavy tools. I had been looking for them for weeks. I have three decanters and there were the stoppers for two of them. I have not found the third one yet.

One of the problems with having such a bad memory is the unbelievable waste of time spent looking for things or having to retrace my steps. My daughter said that I had recently called her to ask if she had ever heard of Spalding Grey. I then went on about how fascinated I was with him. She said that not five minutes after we hung up, I called back and started the whole conversation again. I confess to being unable to remember some conversations at all. Some, I can vaguely remember bits of.

If I want to call someone, I might head for the phone and walk right past it and only later remember my intention. Or I head for the bathroom to take my pills, and it might take a few false starts before I remember to take them. I might forget altogether or I might not.

There is no rhyme or reason to my problem. I can’t even say ‘Well, I remember these kinds of things but have a hard time remembering those kind of things.’ There’s no clear pattern. Today I may be fine and then tomorrow not so fine.

One thing is that I’m as garrulous as ever! Sometimes there is a word-finding problem. Then I may be able to use a substitute. But, since this happens fairly often, I am not hesitant to ask ‘you know, that thing in the garden made of wood and with leaves on it. What’s it called?’

This last week has been a bit discouraging as I again went shopping without any money. In the past, I would have gone to the bank after doing that. But this time, without going to the bank, I tried to go shopping again, forgetting each time that I still didn’t have any money.

I have had very embarrassing moments at the bank – so much so that I was ready to change banks. Yesterday was a nightmare. I went in and told the teller I wanted to deposit a cheque but it had disappeared. We looked under the desk. I went through my purse, which was full of stuff. It was nowhere to be found. I was starting to get upset. The cheque was for $2,000. We looked everywhere.

When I got home I immediately started looking through the papers in my room. Beside my computer was a deposit slip for $2,000 from the day before. I couldn’t believe my eyes. It made no sense. How could I absolutely believe that I needed to deposit that cheque when I had already done it? The worst feeling is that of not being able to trust yourself.

I went shopping yesterday and left the keys in the car and the engine on. I’ve had to have my poor car broken into so many times that the door is practically wrecked. I have an extra key. All I have to do is remember to take it with me and then not to lock my purse in the car as well.

The worst feeling is that of not being able to trust yourself.

One of the problems with having such a bad memory is the unbelievable waste of time spent looking for things.
Congratulations to Alzheimer’s Association Japan (AFCDE) who celebrated their 20th anniversary in June. Nori Graham, chairman of ADI, joined over 600 people who came from all over Japan for the celebration in Kyoto.

It was in January 1980 that 90 people, including family caregivers and professionals, gathered in Kyoto and established the association. At that time, the word dementia was unfamiliar amongst the public in Japan and the question of social services had not yet become an issue. Family caregivers cared for people with dementia at home under extremely difficult conditions. The Association began with regular support group meetings, a help-line and a monthly newsletter. As the number of members increased, several chapters were established in other cities.

During the last two decades, the Association has conducted surveys about wandering, younger people with dementia, use of restraints in facilities and the introduction of long term care insurance. The Association became a member of ADI in 1982 and has continued to exchange information with members since then and is looking forward to hosting ADI’s conference in 2004.

Four years ago, Alzheimer’s Association Korea opened the Songpa Senior Welfare Service Centre (SSWSC) - a multi-faceted service facility. This six-story centre includes a helpline service and two day care centres; one for people with dementia and one for those who have had strokes. There is also a short-term care facility providing respite care (for 3 to 6 months) for 25 elderly people. Other services provided at SSWSC include a safe return program, family support groups, sale of senior care products, performing community services, training helpline specialists, and road campaigning for dementia awareness.

The Songpa facility also provides care for healthy seniors. There are fifty activities to choose from, eg traditional Korean dancing, calligraphy on rice paper and horticulture. There are 130 volunteers who...
assist at the centre and it is through their enthusiastic support that they are helping to spread dementia awareness. People with dementia also enjoy the volunteers as interacting with different kinds of people brings pleasure. The outcome is a person with a positive attitude who contributes in uplifting the community and slowly but surely, the association is noticing the stigma of dementia disintegrating.

Alzheimer’s Association Korea say ‘the encouraging results are due to us becoming an ADI member and sharing their updated information. The resourceful information has helped us to create our own unique method of care.’ The government has also been supportive in raising awareness and the Association is hoping to encourage the development of other chapters in Korea.

NIGERIA

The Alzheimer Association of Nigeria held their first Annual General Meeting from 11-13 May in Anambra. The opening ceremony received wide media coverage throughout Nigeria, which resulted in a sharp increase in awareness. The association now has six volunteer regional co-ordinators who are trying to establish branches in each of their regions.

UK

The International Psychogeriatric Association and the Royal College of Psychiatrists jointly hosted a meeting on non-Alzheimer Cognitive Impairment in Newcastle from 5-7 April. This meeting highlighted the importance of investigating mechanisms of cognitive impairment in conditions apart from AD, and emphasized the growing need for the development of rational treatments for these disorders. For more information about this meeting email: ipa@ipa-online.org

HONG KONG

The Hong Kong Alzheimer’s Disease and Brain Failure Association has received generous sponsorship from the Keswick Foundation for the coming three years, enabling them to rent an office and employ various members of staff to run the office. The association will also employ a part time driver later in the year when they start a day respite service.

Keswick Foundation has a close relation with Jardine Company, which has had an important commercial presence in the Far East for over a century and has funded many worthwhile projects in Hong Kong including help for single parents. The Foundation has been able to give the Association practical help and advice on a number of matters, including searching for an appropriate office, initiating a Christmas card fundraising campaign, passing on their skills and knowledge on fundraising, and providing a consultant to be on hand during the first year.

The help is timely not only for the association (which was set up five years ago) but also for Hong Kong, where there is a slightly higher elderly ratio than in neighbouring areas. Here people over the age of 65 make up 10.5% of the total population. The Hong Kong Government and non-governmental organisations have jointly expanded services for dementia over the past few years. The association is very glad that carers in Hong Kong have had their voices listened to.

LATIN AMERICAN REGIONAL MEETING

The Cuban Alzheimer’s Association hosted the 3rd Latin American Regional ADI meeting last March in Havana. The meeting brought together 11 ADI members as well as several potential members who were able share experiences and learn about other association in the region. Members also ran workshops, in Spanish, on fundraising and how an association can identify its aims.
 Spotlight on Malaysia

The Alzheimer’s Disease Foundation Malaysia (ADFM) recently organised a very successful four day course on Alzheimer’s disease (AD). Participants consisted of family caregivers, healthcare workers, social workers and some interested members of the public. Most participants came away from the course with a much better understanding of AD. They particularly enjoyed the workshop sessions dealing with stress and ways to cope with it; and on the pros and cons of nursing homes.

There was also an obvious relief among caregivers new to ADFM to find an organisation to turn to. One caregiver commented, ‘I went home and applied what I learnt from the course, and spent a very pleasant evening with my mother’. Soon after the course, ADFM also launched their support group with a family fun day. Despite the torrential downpour, around 80 people attended. The gathering kicked off with an exercise session designed to give caregivers an exercise program they can do (adjusted as necessary) at home with the person they are caring for. There was also a drawing session to test the person with dementia’s hand-eye coordination. There was plenty of time throughout the day for people to chat with one another and share stories and ideas on caregiving. And judging from the way people sportingly took part in the activities, most seemed to have had a good time too.

With their greatly enlarged family of caregivers and supporters, ADFM is now looking forward to extending its scope of activities throughout Malaysia.

---

The Croatian Association for Alzheimer’s Disease was started on 7 May 1999. The association’s aims are to:

- provide information
- educate caregivers, family members and members through counselling, lectures and seminars
- establish contacts between families, caregivers, professional workers and people with dementia
- publish manuals, brochures, help sheets and other written materials
- raise public awareness through media interviews

So far, the association has organised several lectures for family members and caregivers, published a booklet entitled ‘What we have to know about Alzheimer’s disease and other dementias’ and set up a web page.

The association has about 100 members who are mostly family members, caregivers, nurses, social workers, doctors, and lawyers and who all have one wish in common: to help and improve the quality of life of people with dementia and those who care for them. If you wish to contact the association, please email Bojana Coric (bojana@hi.hinet.hr).
Preparations are now well underway for World Alzheimer’s Day. As many of you may know by now, the theme of this year’s bulletin is quality of life and what that means to a person with dementia and their carers. We are delighted that Dr Gro Harlem Brundtland, Director-General of the World Health Organization has been able to contribute a message urging governments to recognise and assist carers in their task by improving services and provide financial as well as other types of support.

If you are interested in participating in an event, please contact your local Alzheimer’s association and find out what they are planning. If you are unsure of their address, why not drop us a line and we will be able to give you contact details for the national Alzheimer association in your country: ADI, 45/46 Lower Marsh, London, SE1 7RG; tel +44 (0)20 7620 3011; fax +44 (0)20 7401 7351. Alternatively, you will find these on our website under ‘members’ www.alz.co.uk.

Become a friend of ADI
Please support Friends of ADI by making a donation.

Name

Address

I wish to make a donation of £ __________

If you are a UK taxpayer, we can reclaim tax on your donation under the Gift Aid scheme. Please sign and date below to allow us to do this.

I am a UK taxpayer and would like Friends of ADI to reclaim tax on my enclosed donation: Yes ☐ No ☐

I understand that UK income tax, capital gains tax or the equivalent has been paid on this sum.

Signed __________ Date __________

Please make your cheque payable to Friends of ADI and send to

Friends of ADI
45/46 Lower Marsh, London SE1 7RG, UK
Tel: 020 7620 3011   Fax: 020 7401 7351
Email: adi@alz.co.uk   Web: www.alz.co.uk

Charity registration number 1076992
Exercise offers important opportunities for socialisation which has been found to be particularly valued by older people. Communication and social acceptable touching that are unconnected with personal care, happen naturally in the process of assisted walking, partner work, group ball games, handling equipment, bringing emotional and social benefits as well as improving recall. For carers and the person with dementia keeping active is important not only because it broadens those vital safety margins but also because stimulation and social integration bring an improved quality of life for all concerned.

Physical activity is both functional and fun and brings important health benefits at any age. The correlation between physical fitness and physical health and well-being gives it a high priority in the lives of all those involved in dementia care. Of particular importance is the protection exercise offers against falls through improved balance and strength, the reduction of depression and loneliness and improvements in sleep, alertness and energy through improved endurance and a more active lifestyle.

**Frequency**

At any age:

- 30 minutes of at least moderate intensity activity 5 days a week will significantly improve health
- two 15 minute periods of moderate activity a day can give some health benefits
- maximum benefits will probably be gained with 20 minutes of vigorous endurance activity 3 times per week plus 20 minutes of strengthening 2 times per week plus daily stretching, balance and co-ordination activities

**BUT!** Remember any activity is better than none. Every little counts towards the 30 minutes activity total. To begin with take a ‘little and often’ approach. Begin with

---

**For optimal results exercise should be regular, safe, effective and fun**

---

**Exercise tips for people with dementia & their carers**

**Exercise and dementia**

SUSIE DINAN, SENIOR CLINICAL EXERCISE PRACTITIONER IN THE OLD AGE PSYCHIATRY DEPARTMENT AT THE ROYAL FREE HOSPITAL, UK

---

---
3 minutes, progress to 5, then 5 minutes twice a day and increase to 10 and so on. Once a week is better than nothing and it’s never too late to start.

**Safety**
- always begin your exercise session with a warm up and end with a warm down phase
- aim to build to a brisk pace in the middle phase of the activity but initially give ‘active breaks’ by slowing the pace a little to re-energise and then return to the brisker pace, then ease off again

**Mobility**
- avoid sitting for more than 30 minutes at a time. Just getting up and moving about for 2-3 minutes, walking, upward stretching, marching on the spot and doing some specific controlled mobilising of shoulders, spine and ankles can make all the difference. Mobility work can be done as often as you like and should be in addition to more dynamic activities such as walking, gardening and ball games.

**Routine – Goal Setting**
- set a specific time and days for exercise, whilst it is important to be flexible in order to adjust the time of the activity where necessary, having a set time focuses our attention and assists in the process of seeing activity as part of everyday life - like brushing teeth and washing.
- set specific, realistic short and long term goals – this helps to measure progress and motivate long term ‘good health’ habits

**Variety**
- a ‘mixture’ of activities within each week will bring the best results

**Specificity**
- it is important to have a programme that includes some stamina, strengthening, stretching, bone loading, balance and co-ordination work for as long as possible so as to engage the person in specific postural and functional exercises

**Fitness must be fun!**
Choose activities that are enjoyable. Names, faces, details and movement patterns may not be remembered but associating the activity with enjoyment may help to prompt a positive response next time. Even if there is no memory of previous activity, brightly coloured equipment and music tend to prove irresistible to most - though it may take time each session to engage the person. With music, toes are set tapping, and clapping, swinging marching and dancing.

**We were made to move.** All living tissues, our hearts and our minds, benefit from regular activity and shrink, weaken and breakdown when movement stops. Everyone has the need and right to move. Carers in London, England who began a fitness programme found they had more energy, felt stronger and less exhausted, less stressed, slept better and were more ‘fit’ to care. A study of health professionals showed that those who were physically active themselves were more effective in persuading their patients to be more active for their health. More people, more active, more often is the motto for the Millennium but particularly important for all of us involved in dementia care.
WAC 2000 highlights

From Washington to Beijing there were headlines about Alzheimer’s disease during World Alzheimer Congress (WAC) 2000. The three key events of the congress, pivotal research, bridging research and creative care brought together delegates from over 50 countries with change in mind - change that will lead to new, integrated ways of thinking about the entire spectrum of dementia.

The three events were:

Pivotal Research, July 9-13, which featured the latest dementia research, including updates on a potential Alzheimer vaccine, new therapeutics and advances in imaging.

Bridging Research and Care, July 13-14, provided physicians and other health care professionals with the most up-to-date scientific knowledge and information about diagnosing, treating and caring for people with dementia.

Creative Care, July 15-18, which included the 16th Alzheimer’s Disease International, 9th National Alzheimer’s Education and 22nd Alzheimer Society of Canada conferences, brought together an international community of experts dedicated to caregiving issues. This portion of the congress really encouraged delegates from different care settings to come together and learn from one another. Sessions were targeted at three specific audiences - professional caregivers, family caregivers and the staff/volunteers of Alzheimer’s associations around the globe.

International showcase

The international showcase during creative care, literally gave delegates the opportunity to walk around the world and learn about the activities of ADI members and chapters of the Alzheimer’s Association USA. This interactive session was attended by over 500 delegates and gave many the chance to catch up with old friends and make new ones.

Global impact of dementia

Martin Prince, the coordinator of ADI’s 10/66 group gave the opening plenary of Creative Care on the global impact of dementia. This
very informative presentation really brought home that there are 18 million people with dementia in the world and most of them and their families live in developing countries where there are limited resources and little support available. This was reinforced by Catalina Tudose of Romania in the second plenary of creative care. She movingly described the situation for people with dementia in Romania, and what advances in research really mean to those in less developed parts of the world. In the same plenary, Serge Gauthier of Canada brought us up to date with the latest research and where this is likely to lead us.

**Entertainment**

David Hyde Pierce, star of the hit TV show Frasier and whose grandfather had Alzheimer's disease, hosted the main social event of creative care, the Caring around the world dinner. Maureen Reagan spoke powerfully about her father, former President Ronald Reagan, and the impact of Alzheimer's disease on her family. The evening really went with a swing, as delegates enjoyed the chance to let their hair down on the dance floor to live music performed by the legendary Ben E King, whose father had Alzheimer's disease.
WAC 2000 highlights (continued)

Workshops

Fifteen workshops on organisational issues were run during the conference, these were organised jointly by the conference hosts and provided staff and volunteers from Alzheimer associations worldwide with a stimulating learning environment.

International interaction

The educational sessions and break times gave participants the chance to really learn about each other’s experiences and network, summed up by a carer from Virginia, USA who said ‘I had no idea this was such a worldwide problem, I don’t feel quite so alone as when I first came here’.

The conference was drawn to a close by Edward Trushke, President and CEO of the Alzheimer’s Association USA, who reminded us that the global Alzheimer movement is all about ‘ordinary people doing extraordinary things’.