



Global Perspective

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

Sharing and learning new skills

Alzheimer's Disease International brought seven more countries together in London for the Alzheimer University training programme in March



Lesley Gregory, Lu-ning Wang and Neal Sampson at the Alzheimer University

Representatives from the People's Republic of China, Panama, Slovenia, Hungary, Zimbabwe, Serbia and Montenegro, and Guyana joined the training designed to bring participants to a basic level of awareness and skill on how to set up and run an Alzheimer association.

The programme kicked off with a welcome reception on Friday evening. This not only gave participants an opportunity to meet the ADI staff, it was also a chance for them to meet each other. Participants were soon exchanging

the hows and whys with one another and quickly picked up that although they had come from the four corners of the world, they had much more in common with each other than differences. Frances Stanbury from Zimbabwe summed up the situation facing most of them by talking of the lack of information available when her mother was diagnosed with Alzheimer's disease 'I went to the library but could not find anything. Not even my doctor knew anything about it.'

The sharing and learning continued through the weekend. Interactive workshops were facilitated by people with practical and working knowledge of their topic and included role of the board, how to raise money, how to recruit volunteers, providing information and how to raise awareness. As Beverley Stuart from Guyana said 'the workshops were very informative and my organisation shall benefit tremendously. This is a great help to weaker organisations.'

The programme ended with a strategy day in which participants identified some realistic objectives to focus on for the coming year. They have been encouraged to meet with the rest of their board once they returned home to agree three of these objectives as well as share what they learnt over the weekend. As with previous Alzheimer Universities, participants have been encouraged to stay in touch with each other through email and their progress will be evaluated at six and 12 months.

The Alzheimer University training programme is as motivating for ADI staff as it is for the participants. Not only does it put a face to the email name, it brings to life why people set up associations and the difficulties they face in their countries. For the participants, the comments of Aleksandra Parojcic from Serbia and Montenegro encapsulate the benefit of bringing people together; 'Now I'm feeling as a member of a 'world team' who are working on the same problem. In front of me is a challenge to strengthen our national society.'

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Alzheimer's Disease International

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Send us your comments

If you have any comments about our items for the newsletter 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.

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Updates in dementia research

We are introducing a new column 'Updates in Dementia Research' commencing in the next issue of Global Perspective. This feature, edited by Richard Bonwick, consultant psychiatrist at the Austin and Repatriation Medical Centre in Melbourne, Australia will bring you a summary of the latest research and developments and point you in the direction of further reliable information.

ANNOUNCEMENTS AND CONFERENCES

18-20 April 2002 Alzheimer Society of Canada's 24th National Conference

In Step Together
Calgary, Canada
Tel: +416 488 8772
Fax: +416 488 3778
Email:
conference@alzheimer.ca
Web: www.alzheimer.ca/english/newsevents/conference-intro.htm

27-30 April Alzheimer's Association 14th Annual Public Policy Forum

Washington DC, USA
Tel: +1 202 393 7737
Fax: +1 202 393 2109
Email: info@alz.org

1-4 June XIth Alzheimer Europe Conference

Commitment to care
Maastricht, The Netherlands
Tel: +31 43 361 9192
Fax: +31 43 361 9020
Email: cal.conferenceagency@wxs.nl

20-25 July 8th International Conference on Alzheimer's Disease and Related Disorders

Stockholm, Sweden
Tel: +1 312 335 5813
Fax: +1 312 335 5781
Email: internationalconference@alz.org
Web: www.alz.org/internationalconference

5-8 September 5th Asian Pacific ADI Regional Meeting

Kowloon, Hong Kong
Fax: +852 2338 0772
Email:
gemma@hkuspace.hku.hk
Web: www.hkada.org.uk

12-14 September 2002 3rd Deutschen Alzheimer Gesellschaft Kongress

Acting Together
Friedrichshafen, Germany
Tel: + 30 31505733
Fax: + 30 31505735
Email: deutsche.alzheimer.ges@t-online.de
Web: www.ctw-congress.de/alzheimer

3-5 October 2nd International Symposium on Alzheimer's Disease in the Middle East

Antalya, Turkey
Tel: +1 773 784 8134
Fax: +1 208 575 5453
Email: meetings@worldeventsforum.com
Web: www.worldeventsforum.com/alz.htm

23-26 October 18th Alzheimer's Disease International Conference

Dementia: meeting the
challenge together
Barcelona, Spain
Tel: +34 93 201 7571
Fax: +34 93 201 9789
Email: support@suportserveis.com
Web: www.suportserveis.com

23-26 October IPA's Asia Pacific Regional Meeting

Dementia, Depression, and
Suicide in the Elderly: Cultural
and Clinical Aspects
Hong Kong
Tel: +1 847 784 1705
Fax: +1 847 784 1701
E-mail: ipa@ipa-online.org
Web: www.ipa-online.org

Editorial

Elizabeth Rimmer, Executive Director, Alzheimer's Disease International



'We've got a big problem in China – there are 5 million people with dementia and we've just started the Alzheimer association' Professor Lu-ning Wang, Secretary General of the Chinese Association of Alzheimer's Disease and Related Disorders said to me last weekend at our 4th Alzheimer University. Far from being daunted by the phenomenal task ahead, Lu-ning and her committee of eight are rising to the challenge and have identified raising awareness as the most important aim of their newly established association. The purpose of the Alzheimer University is to encourage participants to learn from one another in how to establish and develop their Alzheimer associations. However, I think all members and in particular our established members have much to learn from emerging Alzheimer associations. I wish every member of ADI had been with us, to

be in a room with representatives from seven diverse countries, all facing economic or political challenges, to hear their stories of why they came to be involved and what drives them to develop their associations, despite the odds being stacked against them. Perhaps for those of us who live in resource rich countries, it is a powerful message to be reminded that you don't always need a lot of money to really make a difference, what you need are passionate, committed and innovative people who are prepared to give their time and energy. If there was some way to bottle the Alzheimer University experience and distribute it to everyone, opening the bottle and having a sniff on those days when we feel uninspired might help us rediscover what led us to become part of the dementia movement in the first place.



ANSAR QAYYUM from Pakistan

My hero – my Dad

I was 18 when my father got ill. It may seem strange but now that he has gone, I only remember him when he was well during those 18 years of my life. I remember the things that he taught me about life and the time that we had together. I recall the first day he taught me how to kick a soccer ball, how to head the ball and how to kick it, so that it stays along the ground and keeps straight. My father gave me courage to face life, he gave me strength, he told me to believe in myself and never to give up even when the odds are against me. I remember that once I had a school exam, it was social studies and I wasn't even fully prepared for it. I was scared and my father came to me and said that it wouldn't matter to him even if I failed at least he would have the satisfaction of knowing that his son had tried. I took the exam and passed, I made him proud of me.

My father was a doctor, he worked for the ruling family of United Arab Emirates. He spoke and wrote several languages. He was well respected by his peers and undoubtedly he was my hero. I aspired to be like him and to have a personality like his. He was strong, immaculate and a very tough cookie. He fought the disease for 14 long years.

I remember the first time I went with my father to the doctor. The doctor gave him a few verbal tests like counting backwards or telling the time. While counting backwards my dad got stuck and I was there in the room with him and I also knew that he was embarrassed; embarrassed that he could not perform this simple task in front of his son. While going home that day we both had tears in our eyes.

I never wanted to give up on my dad, that was what he had always



Ansar (left) with his parents, brother and sister

taught me. I read the newspaper in the morning while my mother fed him breakfast. After starting my first job in a brokerage firm, I used to come home and tell him about my day's experience, hoping for some sort of response, some sort of advice, but it never came. It may be hard to believe that I even tried teaching him how to drive a car again. I desperately failed. Day by day I lost my father further to this terrible disease. We tried everything, every new medication that came

along including the most recent, which in his aggravated state didn't work at all.

My hero, my dad died last July. And every Thursday, the day that he died I go to his grave and tell him about my days experience. I miss him very much. I wish he could be with me even with Alzheimer's.

Now that I am associated with Alzheimers Pakistan I feel as if I am doing something for the sons whose fathers suffer from Alzheimer's disease.

Members' Forum

Germany

Deutsche Alzheimer Gesellschaft recently launched a national telephone helpline for people with dementia and their carers. Funded for the next three years by the Ministry of Seniors, Families, Women and Youth, the helpline received 2,358 calls in the first month. The majority of callers were family carers but the helpline also had lots calls from people who were personally worried about dementia.

Before embarking on this project, the association looked at a number of considerations including room and equipment requirements, whether to use paid staff or volunteers as helpline advisors, and what training the advisors would need.

After consulting with a number of other people who ran other helplines, the association decided to recruit staff to run their helpline and employed three social workers (two of whom are also nurses and

the other is a family carer) and a psychologist on a part-time basis. They are also considering integrating volunteers to assist on the helpline.

Training included a full introduction into the role of other staff members, explanation of the association's structure, what printed information is available, the services the association offers (both nationally and locally) and how to deal with callers and their questions. The advisors were also trained to use the association's database which details all resources about dementia. The aim of the training was to ensure that all helpline advisors have access to the same and simply presented information.

The launch of the helpline was widely publicised in the media which may have explained the overwhelming 2,358 calls during



the first month. Unfortunately, only having two telephone lines meant that the association only answered 550 calls directly and replied to 300 messages on the answer machine. Evaluation of call duration showed that some people were assisted in less than one minute whilst calls from people who felt isolated lasted 30 minutes.

Australia

Recent research has highlighted that people with dementia often have their oral health neglected, both in the community and in residential settings.

A study in Queensland indicated that three out of four people with Alzheimer's disease require dental treatment whilst still residing in the community.

Another report on the status of oral health showed:

- Low provision of care and interest of nursing homes by dentists
- Inadequate treatment room and equipment in residential facilities
- High prevalence of people with no teeth, tooth decay and large accumulations of plaque and food debris.

This study also showed that a majority of residents were cognitively impaired.

There are two major reasons for neglect of oral health care in people with dementia:

- 1 Adequate skills have not been imparted nor integrated into care practices with family carers, community and residential care staff and dental professionals
- 2 Lack of dental services for those on limited incomes or housebound.

Pain from oral problems can be an untreated cause of behavioural symptoms with consequent inappropriate use of psychotropic medicines.

All recent research reports on dental care call for action to achieve oral hygiene care plans for people with dementia, with a holistic approach to the multi-factorial causes of poor oral health.

While some state initiatives in Australia have occurred, overall there has been a failure by the government to maintain or maximise oral health of people with dementia.

For further information about the reports mentioned or the work being done by the Alzheimer's Association of Australia contact Sue Jarrad, Director of Policy Development, Alzheimer's Association (SA) by fax: +61 (8) 8338 3390; or email: alzsa@alzheimerssa.asn.au

Netherlands

Alzheimer Nederland recently issued a dementia discrimination alert following the Health Inspector-General's advice to doctors to consider the risks of treating older people with dementia who may develop complications arising from

a secondary condition and require intensive care treatment.

The association has strongly rejected the idea of denying patients access to medical treatment on the grounds of dementia stating that adequate health care is a basic right for every citizen in the Netherlands.

They have called for more information about problems people with dementia experience whilst being treated for secondary illnesses.

For more information contact Alzheimer Nederland by fax; +31 30 659 6283; or email: info@alzheimer-ned.nl

USA



Robyn Yale, recipient of the MindAlert Award

Congratulations to Robyn Yale who received the prestigious 2002 MindAlert Award from the American Society on Aging and MetLife Foundation. Robyn received the award in recognition for her pioneering work for people in the early stages of dementia, which began with the development of an innovative support group model in 1986 that has been widely replicated nationally and internationally.

Robyn's model was based on her research and clinical findings that showed that many people in the early stages of dementia are willing and able to talk about their experiences when given the opportunity. The approach focuses on remaining capabilities and allows people with dementia and their families to face and work through the emotional and practical challenges of the disease and plan for the future together. This process also enables people with dementia to be involved in family decision-making on their own behalf.

Robyn will be leading a workshop on early stage dementia at ADI's conference in Barcelona, Spain from 23-26 October (see back page for conference details).

POTENTIAL MEMBER

Hungary

The Hungarian Alzheimer Society was set up in 1996 in Bucharest as a support group and was officially registered in October 1999. In the early days, the society concentrated on meeting once a month giving people an opportunity to exchange their experiences of caring and to support one another. They collected materials from more established Alzheimer associations and translated them into Hungarian. Although they have not been able to reduce the psychological, physical and financial difficulties of caring for a person with dementia, they have been able to draw significant public attention about dementia through the media.

Since then, the Hungarian

Alzheimer Society have achieved a number of things, including:

- Signed an agreement of co-operation with the Hungarian Psychiatric Association
- Participated in the preliminary Act on Guardianship in the Hungarian Parliament
- Observed World Alzheimer's Day for the first time in 2001
- Participated in the recent Alzheimer University training programme

However, the Society realises that in order to become more effective, they must recruit more advocates and secure funding.

For more information about the Hungarian Alzheimer Society email ehimmer@matavnet.hu



Eva Himmer, founder of the Hungarian Alzheimer Society, on World Alzheimer's Day 2001

People with intellectual disabilities

The Edinburgh Principles

Heather Wilkinson and Matthew P. Janicki

Dementias generally affect people with intellectual disabilities (ID) in the same manner as they do other older people, except for some differential effects on people with Down syndrome. Adults with Down syndrome are not only at greater overall risk of being affected by dementia but are often affected at an earlier age, and may be affected by steep decline and loss of skills within a shorter period of time.

Currently many practitioners are struggling to find appropriate ways to support people with intellectual disabilities through the progression of dementia. Practices are inconsistent around how to provide these services and supports and many providers have yet to define workable responses to the increasing presentation of dementia among people with ID. A key challenge for care providers is to avoid institutionalisation or the use of inappropriate settings. Underpinning these practice issues is the agreement that adults with intellectual disabilities, as they are affected by dementia, should be treated with respect and given the opportunity to remain in their community with sufficient and appropriate supports and services to compensate for personal losses in function and decline.

These needs and beliefs led to the development of a set of universally applicable guidelines that promote continued community care and support of people with ID affected by dementia. An international Working Group on Dementia Care Practices met in Edinburgh in February 2001

and produced the Edinburgh Principles for use by governments, organisations, and providers.

Background of Effort

Questions raised during a series of meetings held in the 1990s identified the need for a universal set of principles and guidelines on this issue. The Edinburgh meeting involved a number of key international researchers and service providers in the field of ageing and intellectual disabilities. The discussion built on previous work that addressed three key issues involving people with intellectual disabilities: a) diagnosis and assessment of dementia; b) epidemiology of dementia; and c) care and management practices. Reports on these key issues are available through the auspices of the American Association on Mental Retardation (www.aamr.org) and the International Association for the Scientific Study of Intellectual Disability (www.iassid.org).

Conclusion

The Edinburgh Principles mirror to a degree guiding principles for community care of people with dementia in the general population and reinforce the notion that people with intellectual disabilities affected by dementia experience the same type of challenges and can benefit from the same types of progressive services. Overall, the Edinburgh Principles aim to provide a useful and detailed baseline from which further discussions, research and practice development can progress both within the dementia care and the intellectual disabilities care communities.

The Edinburgh Principles

1 Adopt an operational philosophy that promotes the utmost quality of life of persons with ID affected by dementia and, where possible bases services and support practices on a person-centred approach.

2 Affirm that individual strengths, capabilities, skills and wishes should be the overriding consideration in any decision-making for and by persons with ID affected by dementia.

3 Involve the individual, her/his family, and other close supports in all phases of assessment and services planning and provision for the person with ID affected with dementia.

4 Ensure that appropriate diagnostic, assessment and intervention services and resources are available to meet the individual needs, and support healthy ageing of persons with intellectual disabilities affected by dementia.

5 Plan and provide supports and services that optimize remaining in the chosen home and community of adults with ID affected by dementia.

6 Ensure that persons with ID affected by dementia have the same access to appropriate services and supports as afforded to other persons in the general population affected by dementia.

7 Ensure that generic, co-operative, and proactive strategic planning across relevant policy, provider and advocacy groups involves consideration of the current and future needs of adults with ID affected by dementia.

Dr. Wilkinson is the Royal Society of Edinburgh Personal Research Fellow currently based at the Centre for Social Research on Dementia, University of Stirling, Scotland.

Dr. Janicki is associate research professor and director for technical assistance at the University of Illinois at Chicago's Rehabilitation and Research Training Center for Aging with Developmental Disabilities.

Early Alzheimer's An international newsletter on dementia

The Santa Barbara Chapter of the Alzheimer's Association (USA) produce this quarterly international newsletter targeted at people in the early stages of dementia and professionals working in this field. The publication is committed to bringing the best educational and service programmes to the dementia care community.

Early Alzheimer's covers a wide range of programme models offering discussions on issues that address the needs of people in the early stages of dementia. The newsletter also brings news from both professionals and people who have been diagnosed with dementia.

Robyn Yale started the newsletter in 1995, which was then called "International Forum on Early Dementia". Robyn saw the newsletter's role as:

- raising awareness and advocating for change in the way people with dementia were treated
- providing information, support and resources to professionals who worked in isolated areas within their regions
- encouraging communication and collaboration between those working and/or interested in early stage dementia.

Production of Early Alzheimer's was taken over by the Santa Barbara Chapter of the Alzheimer's Association in 1998. Jeanne West, the current editor welcomes submissions from around the world. For more information or to submit an article please contact Jeanne West, Early Alzheimer's, 2024 De L Vina Street, Santa Barbara, CA 93105, USA or FAX: (805) 965-0998 or e-mail jw@jeannewest.com

World Alzheimer's Day 2002

Old age or disease? Recognising dementia

Preparations are underway for World Alzheimer's Day on 21 September. The focus for this year's campaign is recognising the symptoms of dementia. Alzheimer associations and individuals around the world will use the day to raise the profile of dementia and the ways in which their association can help people with dementia and their carers.

World Alzheimer's Day was launched with the support of the World Health Organization in 1994. Production and distribution of materials are co-ordinated by ADI.

To make World Alzheimer's Day a truly international event recognised throughout the world, we encourage you to organise an event in your community. Why not consider having a tea/coffee morning and distributing some bulletins to your guests? Or you could make a point of mentioning that it's World Alzheimer's Day to 10 people you meet on 21 September.

Perhaps you would like to volunteer to co-ordinate an event on behalf of the Alzheimer association in your country? If so, why not get in touch with the national office and see how you can help. You can visit ADI's website www.alz.co.uk or contact the secretariat to find out their contact details.

The Alzheimer Association in Uruguay on World Alzheimer's Day 2001



Order your World Alzheimer's Day pack

Please complete and return this slip to receive a World Alzheimer's Day pack. The pack costs £10/US\$20 and contains: 20 bulletins · 5 posters · 50 postcards · 50 badges · 50 stickers · 50 bookmarks · 10 balloons

Do you wish to receive your materials in English or Spanish ?

UK cheques for £10 should be made payable to Alzheimer's Disease International (if you are ordering from outside the UK, please send a bankers draft for \$US20 – we are unable to accept non-UK cheques).

Please return to ADI, 45-46 Lower Marsh, London, SE1 7RG, UK

Name _____

Address _____

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ADI Annual International Conference

23-26 October 2002 · Barcelona · Spain

Dementia: meeting the challenge together

ADI welcomes you to our 18th annual international conference hosted by the Confederacion Espanola de Familiares de Enfermos de Alzheimer y Otras Demencias (CEAFA). Over 3,000 people are expected to attend the three-day conference whose programme will look at quality of life issues and the global impact of dementia. And in recognition of the fact that Barcelona is synonymous with the work of Gaudi (one of the most celebrated Spanish architects around the world), the conference will examine the importance of design/architecture in dementia care. Sessions will be in English and Spanish. Deadline for the call for abstracts is 31 May.

For more information about the conference contact:
Production and Technical Secretariat
Suport Servicios SA
Calvet, 30
08021 Barcelona, Spain
Tel: +34 93 201 7571
Fax: +34 93 201 9789
Email: support@suportserveis.com
Web: www.suportserveis.com

Meeting the challenge of dementia in Spain

CEAFA have been the voice of people with dementia and their carers in Spain for the past 12 years. The association was formed when two separate groups in Madrid and Barcelona joined forces. CEAFA has now grown into a confederation of 99 autonomous Alzheimer associations representing some 450,000 people with dementia in Spain.

The role of the national office, based in Pamplona, is to:

- Support branches by co-ordinating activities
- Collate and distribute national and international resources to branches
- Raise national awareness about dementia
- Represent the rights of people with dementia and their carers

CEAFA work towards achieving their aims through a range of activities including observing World Alzheimer's Day, seminars, producing a carers manual and guidelines helping their branches develop group activities. They have recently launched their first national newsletter.

The association receives support for its programmes from the government, Foundations, banks and other companies. These have



Members of the conference organising committee welcome you to Barcelona

included developing home help programmes, personal safety and safety in the home programmes and recruiting volunteers programme.

In 1999, CEAFA received the Golden Cross of the Orden Civil de la Solidaridad by the Ministry of Employment and Social Services in recognition of the home help programme the association set up throughout Spain.

Future projects include branch guidelines on setting up and running day care centres, and looking at ways in which technology can help people with dementia, especially those in the early stages who have difficulties with spatial orientation.

For more information about CEAFA visit www.ceafa.org

Please support ADI

I wish to support Alzheimer's Disease International and subscribe to the newsletter. I enclose my annual subscription for:

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