

# Global & Alzheimer's Disease International Perspective

WINTER 1996

VOLUME 6 NUMBER 5

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

Report on the October conference in Jerusalem by Shmuel Moran, Conference Chairperson

## 12th International Conference

*The Israel Alzheimer's Association hosted this year's 12th International Conference of Alzheimer's Disease International in Jerusalem from 8th-11th October 1996.*

The conference motto (from the Book of Jeremiah, Chapter 29, verse XI) '...to give you a future and a hope...' indicated the intention that the discussion of the multi-disciplinary topics of the conference; medical, social, nursing, legal-ethical would bring hope for a better future to the sufferers and their families. The international nature of the meeting was outstanding; with over 400 participants from nearly 40 countries throughout the world and with 82 of the 123 presentations given by non-Israelis.

The meetings gave an opportunity to hear experts outstanding in their fields, and the participants had an ideal opportunity to discuss the

complete range of problems involved in this disease.

Presentations included lectures, workshops, symposia and round tables. The first day included a special program, the Tel Aviv University Conference on Alzheimer's disease.

The quality of the presenters resulted in a varied conference program of the highest standard. Simultaneous translation into Hebrew in selected sessions made possible the participation of non-English speaking Israelis.

The conference was also noteworthy for its efficient organization and varied social program, a different event every evening, from the reception for the heads of the

national delegations at the President's residence given by Mrs Reuma Weizman, wife of the President of Israel, the get-together the first evening, and a sound and light presentation at the Tower of David to name only a few. A theatre group from England, 'Mind the Gap' travelled to Jerusalem specially to present the play 'Change of Mind' which portrayed one family's experience of Alzheimer's disease and the changing relationships within the family with sensitivity and understanding.

The Israel Alzheimer's Association took the opportunity to increase awareness in Israel of their work, starting from International Alzheimer's Day in September there was coverage in the written press, on radio and during the conference also on national television.

LEFT TO RIGHT Professor Amos Korczyn, Ruth Goldberg, Teddy Kollek (former Mayor of Jerusalem), Brian Moss, Dr Shmuel Moran





## ANNOUNCEMENTS

### CONFERENCES

#### American Society on Aging Conference

December 4-7 1996  
San Diego, California  
*Bridging the many worlds of case management*  
Tel: +1 415 974 9600

#### International Institute on Aging Conference

December 12-14 1996, Malta  
*Eliminating poverty in old age - a developing country perspective*  
Tel: +356 243044/5  
Fax: +356 230248

#### Alzheimer's Disease International 13th International Conference

29 September - 1 October 1997  
Finlandia Hall, Helsinki, Finland  
Main themes: advances in the care of dementia, new perspectives on services development, innovative approaches to supporting family carers, human and legal rights of those with dementia  
Contact: Alzheimer Society of Finland  
Tel: +358 9 6226 2013  
Fax: +358 9 6226 2020

#### Alzheimer's Disease International 14th International Conference

Cochin, India  
*Dementia - the Global Challenge*  
Dates to be announced  
Contact Conference Secretariat  
Tel: +91 488 522939  
Fax: +91 488 522347

#### Fifth international Geneva/Springfield Symposium on Advances in Alzheimer Therapy

April 15-18 1998  
Geneva, Switzerland  
Tel: +1 217 782 7711  
Fax: +1 217 785 4413  
Email: ogden@wpsmtp.siumed.edu

### PUBLICATIONS

#### Learning to Listen

By Maggie Comley  
A book on counselling skills for helpers of older people. Aims to help carers meet some of the emotional demands made of them as they build trusting relationships with their clients. Published by Helpage International, 64-74 Saffron Hill, London EC1N 8QX  
Tel: +44 171 404 7201  
Fax: +44 171 404 7203  
Email: helpage@gn.apc.org.  
Price: £5.95 plus postage (UK £1.00, Europe £1.20, World £2.00)

#### The Alzheimer's Disease Society's Quality Assurance Initiative

A booklet which explains the Alzheimer's Disease Society's (UK) innovative and exciting quality assurance initiative within the care services that its branches run. For further information and copies please contact: Care Consortium, Alzheimer's Disease Society, 45-46 Lower Marsh, London, SE1 7RG.  
Tel: +44 171 620 3001  
Fax: +44 171 928 2193

#### Relationship between Neuropathological Hallmarks and Neuronal Activity in Alzheimer's disease

By Ahmad Saleh  
A postmortem study on the human hypothalamus and hippocampus. Published by Netherlands Institute of Brain Research. For copies contact: Netherlands Institute for Brain Research, Meibergdreef 33, 1105 AZ Amsterdam ZO, Netherlands

#### US Alzheimer's Association public policy brochure

Now available. For copies, contact US Alzheimer's Association.  
Tel: +1 312 335 5731  
Fax: +1 312 335 5186

#### Publications list

We are compiling a list of publications about Alzheimer's disease and other dementias available in member countries. Please send in details of publications for inclusion to the Secretariat.

## Global Perspective

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## A report from the 12th Alzheimer's Disease International conference in Jerusalem, 1996

# A call for 'back to basics'

Noreen Siba (UK), former Director of the Alzheimer's Disease Society of England and Wales

### Sessions on setting up a society

Amidst this year's very successful Alzheimer's International Conference and the many fascinating scientific and caregiving lectures, I gave a short presentation on 'Setting up, running a national Alzheimer's disease organisation'. Also, I held with the Director of the Israeli Association a surgery on 'Building an Alzheimer's Disease Society'.

These sessions went very well and were attended by developing countries whose societies were not yet formed or were in their early stages of development, some experiencing enormous difficulties in gaining support, resources, awareness, let alone credibility.

### Opportunity for discussion

I soon received feedback from participating countries that although the presentation was well received much more valuable was the opportunity to have time to openly discuss together common problems, ideas and practical suggestions for developing an Alzheimer's Disease Society.

Having already felt this reaction to my first presentation I agreed with the Director of the Israeli Association that I would use the surgery time to

facilitate a round the room discussion. We asked each country attending to introduce themselves and highlight the main issues that concerned them about building a society.

The countries attending included Brazil, Colombia, Germany, Guatemala, Poland, Romania, the Bahamas, the Czech Republic, the Ukraine and the UK. The key points raised by such an interesting range of countries enabled me to create a useful agenda of items for discussion.

The time spent was so rich and practically helpful to those present that immediately afterwards some of the countries appealed to us to request many more sessions of this type in future conferences so that these opportunities could be extended to many others.

### Key issues

I spent the next breakfast time presenting the key issues that we discussed in our surgery as suggestions for workshops at next year's conference in Finland. These are:

- Setting up and developing self-help/support groups
- Team work between professionals and carers. How to make closer link with professionals.



- How to start a society/association. Basic ground rules and the benefit of other's experience in different cultures.
- How to build and develop a society/association to achieve the maximum potential with the resources available.
- Role of publicity in strengthening a society.
- How to recruit (any) volunteers amongst carers and outsiders and provide training for them.
- How to achieve government support for a society.
- How to bring together local organisations to form one national society and achieve better coordination nationwide.
- Models of respite care initiated by a society – for example, day care, respite beds and sitting services.

### Sharing experiences

What is needed is plenty of time for open discussion and exchange of ideas and information in a supportive atmosphere where resource people, experienced in organisational aspects of Alzheimer's Disease Society's work, simply facilitate discussion rather than lead with a lecture.

Coupled with more

opportunities to talk informally with individual countries about the mechanics and work of their societies, this could really satisfy more needs of participants. It would enable them to share the very real problems and basic issues they experience at home and which they bring from great distances when they attend an international conference.

### Market place sessions

Another idea would be to repeat a market place session, as held at a previous international conference, where organisations meet up and have the chance to ask questions and find answers to the problems they encounter in developing an Alzheimer's Disease Society.

It was also felt that teach-ins on some of the basic areas of development – for example, support groups, training, public awareness – would be invaluable alongside discussion workshops.

I do hope this appeal will not go unheard, especially if we expect new countries to keep attending. When travelling so far they deserve to really benefit from the time spent with others who are both struggling and experienced in building national Alzheimer's Disease Societies.

## The way forward

**Dr Nori Graham,  
newly elected Chairman of  
Alzheimer's Disease International**

As the newly elected Chairman of ADI, let me say firstly that Brain Moss, my predecessor, will not be an easy act to follow. He showed leadership and commitment to ADI over many years. Under his guidance the organisation has prospered and grown. Already 40 countries have become members and there are more in the pipe-line.



Alzheimer's disease is a universal problem. There is already much greater awareness in developed countries but awareness is now surfacing in less economically developed countries where populations are rapidly ageing and traditional structure changing. I firmly believe that national Alzheimer's associations can be a strong force and mechanism through which carers can exert a powerful voice about their many needs. However, countries all have differing national traditions, differing attitudes to voluntary action and ADI needs to be sensitive to these differences so that it can facilitate expert help between countries in an appropriate way. ADI needs to act as a resource point for enquiries and requests. ADI, through its member countries, needs to represent the carer when working with other international organisations with similar interests. ADI needs to encourage research. Our international conferences which, uniquely, bring together carers and interested professionals, provide opportunities for carers to hear up dates on research and take part in discussions on matters relating to organisations, clinical and ethical issues.

Governments in every country need to be made aware that Alzheimer's disease is now a major public issue, not the private and hidden tragedy that it used to be and still is in so many parts of the world. The task that lies ahead for all those involved in ADI is to find ways of influencing governments to take seriously the impact of Alzheimer's disease on the individual and the family which is inevitably going to have major implications for health and social services in every country in the world. Every country, whatever its level of economic development, has a major responsibility and duty to put the tragedy of Alzheimer's disease and its consequences high on the political agenda. These are the tasks which face us and which we can all do better if we work together.

*A very happy Christmas  
and our best wishes for  
1997 to all our readers!*



# At some point I started saying 'I' instead of 'we'

An extract from a talk given by Miriam Webber at the 12th ADI conference in Jerusalem

*My name is Miriam Webber. I live on Moshav Habonim, a communal settlement in the Coastal Plain in Israel. I have two married sons who also live on the settlement with three children each, and a married daughter with two children, at present in Pittsburgh, USA.*

## **Nine years in five minutes**

*I have five minutes in which to tell you about more than nine years with Alzheimer's disease. Five minutes to cover two years of denying and then admitting that something was wrong with my husband, before the awful day of the cognitive diagnosis.*

*Six years of caring for him at home until I reached breaking point, the process of putting him into the Institution, and a year and a half of living on my own visiting him.*

*How can I possibly convey in five minutes the realization of shattered dreams for the future?*

*Monty was a talented artist with a teaching Diploma, but during the 36 years that he managed and developed the factory on our settlement, he rarely painted. He would always say 'I'll paint when I retire'. When I realized that he would not be able to paint when he retired, the few canvases in the spare room suddenly became far more precious.*

## **Desperate feelings**

*How can I tell about the deceptions, white lies, close shaves and alibis, to keep him from knowing that he had Alzheimer's disease, the changes I went through as I gradually took over responsibility for both our lives as well as beginning to help him with every single action except eating, the feeling of being a prisoner – able to get away only when someone else looked after him, the sometimes desperate feeling of wanting to escape but being*

*able to do so only by writing stories and poems – and 14 files of diaries.*

## **Milestones in caring**

*The period during which I introduced him gradually into the day centre, while at the same time visiting my only sister who was in hospital dying of cancer.*

*How he slowly lost the ability to speak or write.*

*My emotional change from being a wife to being a nurse.*

*At some point I started saying 'I' instead of 'we'.*

*The help I have had from my children, my grandchildren and friends.*

*The strange rash that appeared on my arms, the ache in my left shoulder and then my right hip; the dreadful scurf I developed and the amount of hair that came out with the special shampoo; the sudden back ache one day, and the way I changed the way I laughed when the doctor recommended 'rest'.*

*How further deterioration in his condition brought me finally to the point where I felt I could no longer care for him at home.*

*With this came the nightmare period of finding a suitable institution and taking him there.*

*The terrible alone feeling when I walked into the house after leaving him at the institution.*

*The times after that when I would wake in the morning and look at the clock in panic – before remembering that I no longer had to get him up and pee him, dress him, wash him, feed him and send him off to the day centre.*

*The fact that it took me more than a year to unwind and learn to live for myself.*

*The freedom of going away and not having to rush back home before the aide leaves.*

*The lingering guilty feeling when I enjoy chamber music concert with somebody else.*

## **At ease now**

*Now when we visit this vacant-eyed person who looks like my husband he smiles, but makes no other sign. He appears at ease. He is clean and well looked after, in a warm caring atmosphere, and my conscience is clear. I did my best for him.*

*I have stayed reasonably sane, kept my sense of humour and survived so far, I hope to survive whatever is still to come.*

## **Horticulture:**

**L**AST SUMMER, flowers in a riot of colours greet visitors to the Homewood Health Centre. Gardening is an important part of the holistic approach to treatment used at the Guelph psychiatry facility. Here, horticultural therapy, therapeutic touch and aromatherapy are used to help residents, along with art and dance.

With grounds stretching over 47 acres, raised flower beds and well stocked greenhouses, Homewood is an ideal location for horticultural therapy. However, many activities in the Homewood program can be adapted to a single room with a southern exposure, says Mitchell L Hewson, Homewood's Director of Horticultural Therapy.

The first registered horticultural therapist to practice in Canada, Mr Hewson led a workshop at the 1996 Forum on Alzheimer Disease organised by the Alzheimer Ontario and



*I received a letter today written by Kathleen, who has recently been diagnosed as having Alzheimer's disease. It is a letter which she has written to her friends in the parish where her husband Stanley is the local Vicar, and which she wishes to share with all of us in ADI.*

*In her letter, which we will be reproducing in our next issue, she says among other things, 'I do not write to gain sympathy, but so that if any of you or your loved ones are unfortunate enough to contract this dreadful disease (and it does happen to younger as well as older people) then you will gain courage from what I have to tell you about my own experience.'*

*This statement from Kathleen underlines the common thread that I always find evident in everyone who is touched in any way by Alzheimer's disease – the eagerness to share experiences, to bring comfort to others, to let others know that they are not alone.*

*This was very evident too in our*

## Reflections from the Secretary General

*recent ADI Conference held in Jerusalem, where delegates from nearly forty countries came to share their own experiences, enriching our knowledge and understanding of the disease and leaving us with very fond memories.*

*Many of you have written in to share some of those memories with us, for which we are very grateful. For those who were unable to be with us in Jerusalem, these letters, some of which we have reproduced on pages 8–9, will give you a good flavour of what you missed and I hope that they will spur you on to joining us in Helsinki next year as we celebrate our 13th annual ADI international conference.*

*Our thanks go to Ruth Goldberg, Shmuel Moran, Amos Korczyn, Shosh Efrat and all the staff at the Alzheimer's Society of Israel for let-*



*ting us share in what was a memorable experience for us all. My thanks also to Gideon Rivlin whose staff, Sharon, Mary and all those other lovely ladies from Kenes, made sure that everything went smoothly.*

*Finally a special thank you to Dr James Warner, who took on the unenviable task of writing up 12 sets of committee meeting minutes, for which I shall be eternally grateful, and to the ubiquitous Beatriz Rose, who helped in many ways. And to all those who came, for their support.*

Robert A Gomez

## a soothing therapy

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the Ontario Nursing Home Association.

He says there are numerous ways horticultural therapy can be used to help people with Alzheimer's disease. "The touch and smell of the earth and the colour of the flowers bring back early memories of a childhood outdoors. Horticulture also offers activities adaptable to different levels of ability which can give people a sense of achievement"

For higher functioning Alzheimer residents, he recommends placing a variety of plants in different sizes,

shapes and textures in a single container. People in the early to middle stages of the disease can collect and press fresh flowers for decorating stationery and candles.

He says even residents in the later stages can become involved if a helper guides their hands so they can plant a bulb or small cutting. If this is too difficult, they might be able to hold a bulb in place while the helper spoons on the soil.

Mr Hewson has observed that residents with Alzheimer's also gain a sense of achievement by doing simple jobs around the greenhouse. "One woman just lives to do the watering".

However, he stresses avoiding poisonous plants and taking care when working with spoons which people with dementia may associate with eating. Mr Hewson also advises choosing plant pots and tables in contrasting colours so they can be

clearly seen. He notes that horticultural activities have the added advantage of enabling staff to assess residents in a non-threatening environment. To give residents pleasure, he suggests bringing a night blooming cactus to the rooms of people who cannot sleep.

He tells the story of a depressed woman who took little interest in an amaryllis bulb she'd been given for Christmas, but when the first bloom appeared she was delighted and moved it to the main lounge where others could see it. She was soon talking and socializing with other residents because of her positive experience.

For more information on horticulture for people with Alzheimer's disease and information on Mitchell L Hewson's book, *Horticulture As Therapy*, write to him at Homewood Health Centre, 150 Delhi Street, Guelph, Ontario, N1E 6KP, Canada.



# Members' Forum

At the ADI conference, Greece, Colombia and the Dominican Republic were welcomed as new provisional members. Hong Kong, Brasil, Guatemala, Venezuela were given full membership status. Congratulations to all of them, we are proud to have them join the ADI community.

## Current full and provisional members of ADI:

Argentina Australia Austria Belgium Brasil Canada Chile Colombia Denmark Dominican Republic Ecuador Finland France Germany Greece Guatemala Hong Kong India Ireland Israel Italy Japan Korea Luxembourg Mexico Netherlands New Zealand Puerto Rico Poland Romania Scotland Singapore South Africa Spain Sweden Switzerland UK USA Uruguay Venezuela

### NETHERLANDS

Aizheimerstichting celebrated World Alzheimer's Day on September 20th by organising a successful press conference in Utrecht. Much media interest was generated by the publication of a video 'There's nothing wrong with me' which shows the link between brain deterioration and behaviour in Alzheimer patients. Three new regional associations were founded on the same day bringing the total number to 31. Earlier in the year, Alzheimerstichting organised a study for family carers, to discuss ethical issues, subjects looked at included the 'autonomy of the demented person' and 'feelings of guilt', a brochure on this will be produced by the end of the year.

### JAPAN

The Chiba branch of AFCDE announced the results of a survey on family caretaking which was done late last year. Fifty percent of those families surveyed have experienced problems with wandering., this ranged from individuals missing from 3 hours to 3 days. Most cases were reported to the police but the majority of those who had gone missing were found by strangers. The report highlights the need for the SOS wandering system to be put into practice in this part of Japan as it has been successfully in other parts of the country.

### SCOTLAND

World Alzheimer's day was marked by Alzheimer Scotland – Action on Dementia with a conference on Dementia and the Law held in Edinburgh. The conference was attended by over 140 people and examined the legal issues relating to welfare, financial matters, treatment decision making and consent for people with dementia. The keynote speaker George Robertson MP gave a strong opening address and called for the rights and independence of those with dementia to be upheld flexibly and sensitively.

### NEW ZEALAND

Congratulations to the Alzheimer Disease and Related Disorders Society of New Zealand who celebrated its 10th anniversary in September. The Waikato branch of ARDAS recently organised a 6 day residential educational course for 10 carers. The content of the course was established in consultation with a carer, professionals and an academic. A workbook for carers was produced focusing on taking care of the carer's needs first and looked at topics such as stress management, relaxation, dealing with grief and guilt, family dynamics, building supportive networks and establishing care plans. Participants valued the need for a residential course which gave them time to talk and to share experiences and ideas with others. The next course has not yet been advertised but there are already two bookings!



## Alzheimer's Disease 13th International

29 September – 1 October 1996  
Finlandia Hall, Helsinki, Finland

### Alzheimer's – the blind hunter

Main themes: advances in the care of  
new perspectives on services developed  
innovative approaches to support families  
human and legal rights of those with  
Contact: Alzheimer Society of Finland  
Tel: + 358 9 6226 2013  
Fax: + 358 9 6226 2020

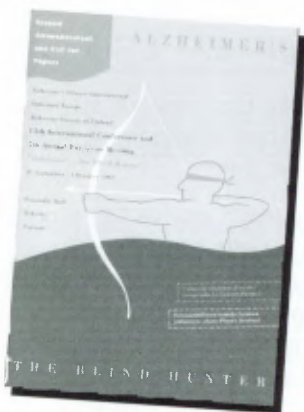
### Provisional speakers and topics

**Harry Cayton:** Hunting in the Dark – wh  
**Sirkka-Liisa Ekman:** Understanding the  
**Margareta Grafström:** Mother-daughter  
**Vladimir Hachinski:** Vascular dementia  
**Arja Isola:** Happy future – human, techn  
**Staffan Josephsson:** Challenges in sup  
**Mary Marshall:** Ethical dilemmas in den  
**Lilia Mendoza:** A family caregiver – eve  
**Astrid Norberg:** Alzheimer's, the blind h  
**Paavo Riekkinen:** Impact of apolipoprot  
**Allen Roses:** Apolipoprotein E in Alzheim  
**Yaakov Stern:** Cortical versus subcortical  
**Leon Thal:** Prospects in the treatment c  
**Peter J Whitehouse:** Global harmonisat  
**Bengt Winblad:** Diagnostic challenges



## Alzheimer's Disease International Annual Conference

of dementia,  
management,  
family carers,  
dementia  
t



What can people with dementia tell us?  
The world of demented persons  
Relationships in dementia  
Conceptual dusk, therapeutic dawn  
Rational, rational? How to choose?  
Supporting family caregivers  
Dementia care  
Everybody's concern  
A caring perspective  
The APOE ε4 phenotype in brain functioning  
Alzheimer's disease - present progress  
Dementias  
Alzheimer's disease - hope in the future  
Development of dementia drug guidelines

### INDIA

The Alzheimer's and Related Disorders Society of India (ARDSI) in collaboration with the Vidyasagar Institute of Mental Health and Neurological Sciences have initiated a six month training programme. ARDSI is setting up respite groups which will involve interaction between relatives of AD patients to increase knowledge and strengthen support systems. Although at the moment contact is via the telephone it is planned to meet once a month and give counselling at Rotary club meetings and other social centres. A day care centre specialising in the care of AD patients is in the pipeline. The problem of funding is the major hurdle as corporate bodies are not responsive and government regulations impede the inflow of foreign donations.

National Alzheimer's Awareness week and its AGM were held. The awareness week September 1-7, focused on the needs of people from diverse linguistic and cultural backgrounds. A local radio station aired a three part series on dementia for nine language groups, Greek, Italian, Arabic, Chinese (Cantonese), Polish, Serbian, Croatian, Macedonian and Vietnamese. The programmes were supplemented with brief articles in the ethnic press. The week was successful in raising awareness about dementia and support available amongst ethnic communities. The AGM was held on September 20 and included a carers morning tea attended by over 100 carers.

### DOMINICAN REPUBLIC

Asociacion Dominicana Alzheimer became provisional members of ADI at this year's conference. The association has just celebrated its second anniversary. It was founded in 1994 following a public meeting about Alzheimer's disease and related disorders. The current president, Mary Guerra was a founder member of the association and was motivated to start it after caring for her mother who had AD for 7 years. She wanted to share her experiences with others. The main aim of the young association is to raise public awareness. Monthly meetings since January 1995 during which talks related to Alzheimer's disease are given, have been well attended by family members, psychologists and the general public. The association also has a programme of school visits to talk to children about AD and answer any questions. One of the main problems facing the Dominican Association is a lack of financial resources which makes the setting up of programmes difficult. To date they have relied on private donations. The association feels that being part of ADI will enable them to pass on scientific advances to members and to share their experiences with other associations throughout the world.

### IRELAND

The Alzheimer Society of Ireland has moved to new headquarters in Dun Laoghaire, Co Dublin. Alzheimer House is a three storey period style house which has been converted into modern offices. The move was necessitated by the huge growth in the organisation. There are now more than 2000 members in 24 branches throughout Ireland. Each branch elects delegates to one of 8 regional committees, which correspond to 8 regional health authorities. Each regional committee in turn elects delegates to the National Council which is the controlling body of the Society. 80 support groups meet on a regular basis nationwide where carers can exchange problems and solutions. The society has developed its own 'Alzheimer Friendly' Day and Respite Care Services which now provide facilities for more than 600 patient days per week.

### AUSTRALIA

The Alzheimer's Association of South Australia, had a busy month in September during which



# Impressions of the conference

A selection of abstracts from the many letters written by members who attended the 12th international ADI conference in Jerusalem.

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## Poland

*Barbara Szczepanowska, Vice President Polish Alzheimer's Association*

'I would like to thank you very much once again for giving me the opportunity to attend your conference in Jerusalem. It was super interesting! The only minus was that it was impossible to listen to all the presentations! But I met a lot of interesting people, had some very fruitful discussions, collected a lot of information and made contacts. Besides listening to ideas and solutions of other people, it makes you think about your own solutions. It gives you the beacon where you should go, which direction to choose, which mistakes to avoid, and shows you where you could be in some years time!'

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## Greece

*Magda Tsolaki, Vice President of Greek Society of Alzheimer's Disease and Related Disorders, GARDA*

'Outside the rooms of the conference sessions, during the opening ceremony, during the lunch time, I met people who tried to organise the society in their countries and spoke to me about their experiences, their problems and their results. Although when I arrived in Jerusalem I knew only some names, I had the opportunity to meet and hear from carers and workers from other parts of the world. I felt enriched by meeting them and I know that by the time the conference ended, I wanted to do more on a national level.'

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## Guatemala

*Haydee Lopez, President, ERMITA (Translated by Beatriz Rose)*

'It was precisely in Israel, a place that I have always admired, that Guatemala had the opportunity to apply formally to become a full member of ADI and after much help from numerous people and a 20 hours flight, ERMITA finally arrived in Israel. Right from the welcome at the airport at Tel Aviv, it could be seen, how well the conference had been organised. Everything was a learning process, a sharing of information and the emphasis in such a noble cause was such a positive experience. People from all over the world working hard and contributing to the conference. Despite being in another continent, we did not feel like strangers but more like part of a large family. Being part of ADI's family.'

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## Germany

*Dr Alexander Kurz, M.D., Medical and Scientific Advisor, Deutsche Alzheimer Gesellschaft*

'For me as newcomer to ADI the Jerusalem conference was an extremely stimulating experience. There were many important messages to take home. One is that in any country powerful national self help organizations do not grow without effort from local activities. National organizations gain internal structure, identity and influence by developing specific programs and services. Another important issue is that such programs can be carried through only by combining arduous idealism, professional expertise, and personal commitment. ADI has managed to pull together these components on an international level and this may serve as a valu-

able model for developments on a national or local scale. A deep and lasting personal impression of the conference was the atmosphere of friendship and encouragement in which I was able to work together with so many excellent colleagues.'

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## Mexico

*Maria Teresa Santesson, President of the Mexican Alzheimer's Association AMAES*

'Once more I assessed, and this I say from the bottom of my heart, that the most valuable experiences and knowledge I have gathered come not so much from the always interesting presentations at the main sessions but from the informal chats and idea exchanging with both caregivers and scientists where the everyday efforts of each of us are warmly and lively shared. It never ceases to amaze me how many people working at the AD associations worldwide are relatives of Alzheimer's patients. It has been, once more, a moving and extraordinary experience to realize how pain and grief, when positively focused, can yield transcendent results.'

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## Ukraine

*Dr Natalia Bachinskaya, Institute of Gerontology, Academy of Medical Sciences, Kiev*

'I very much enjoyed its program, the reports and discussions during and after the sessions and especially those reports which were concerned with the epidemiological, clinical and experimental investigations on Alzheimer's disease as well as a search for adequate treatment approaches. This has permitted me to expand my knowledge and get an insight into this disease from modern perspectives.

In view of the acquired experiences and knowledge, my priority tasks will be the following:

- To increase awareness and understanding of the problems of demented people and particularly AD type cases at all levels (medical, public)
- To create a supporting network for relatives of Alzheimer's disease patients.'



## South Africa

*Dr Jeannie Roberts, Chairman ARDA, Natal Branch, Vice Chairman, ARDA, National Society*

**T**he importance of support for carers was highlighted. In addition the need was discussed for educating and training families, doctors, health visitors and community nurses. A delegate from Switzerland advised that they are also offering training to the police, bus drivers, shopkeepers and the general public.

The feelings of sufferers were not forgotten and a plea for the improvement of the quality of life was made. They need to be loved as their inner core remains intact and they can sense whether the carer really does care or not. Their abilities should be emphasized rather than their disabilities.

I have taken heed of Brian Moss's words in the opening ceremony '... listen, learn, network, share your field of knowledge...' I have made valuable contacts and have also invited Sharon Arkin of the University of Arizona to hold a workshop in Natal when she visits South Africa in 1997.'

## Puerto Rico

*Sandra Jean Rivera, Association of Alzheimer and Related Disorders of Puerto Rico*

**T**his type of endeavour brings the world closer together bonding its nations in a common purpose and a shared painful experience. Language was no barrier. Acknowledgment of the worldwide contributions generates respect for their efforts in trying to deal with this silent epidemic in spite of sometimes of a lack of formal support.

This is an exceptional opportunity for sharing materials, books, ideas, projects and experiences in providing care and services to all our Alzheimer patients and their families. This wealth of information will be used to develop the activities of our Association.

There is pride in knowing that your country is part of this network of efforts which ADI helps generate.'

## Czech Republic

*Dr Hana Janeckova, Post Graduate Medical School*

**I** liked the multidisciplinary and multisectorial approach in the conference. The range of topics was very wide. Next to the discussion on very special and theoretical and scientific issues regarding causes, forms, diagnostics and therapy of dementia there was very practical information on arranging daily activities and improving the quality of life of people suffering from dementia. Each piece of this information was very important, inspiring and hopeful. Unfortunately we could not take part in all parallel sessions and workshops. One of the most practical points was the preconference professional tour. I took part in this excursion and was fascinated by the variety of the activities serving people with dementia and their families in Israel. Dance therapy, occupational therapy, endless patience of the personnel and volunteers in day centres and institutions - a really good example for my country.

And finally I was impressed by the very informal and working atmosphere of the whole conference. The participants were so involved in the programme, their readiness to help was so big and the support of each other was so intensive that nobody could stay untouched.

This enthusiasm and working atmosphere followed the group of people from the Paradise Hotel on their post conference trip to the Dead Sea and had its top on Saturday evening at the hotel's hall. We were sitting and sharing our life stories, experiences, recommendations. We from Prague and Kiev listened and put questions to Barbara and Mirka from Poland and to Suzanne Ogay and other people from Switzerland and Germany. The workshop on the establishing of new Alzheimer's Society, coordinated by Noreen Siba during the conference continued that evening unofficially till late at night.'

## Hong Kong

*Dr Yu Chi Shin, Edwin Chairman Hong Kong Alzheimer's Disease and Brain Failure Association*

**H**ong Kong shall revert from the UK to China in July 1997 and we hope our young association will build a desirable first link between Chinese and non Chinese in the dementia field....I was very glad that the AGM voted to have the admission of Hong Kong as a member of the international body set out to provide a link between member countries and areas, ensuring opportunities for networking and sharing ideas and to assist member countries to provide support for people with dementia and their carers worldwide.'

## China

*Dr Xiao Shifu, Shanghai Mental Health Center, China*

**I**t provided a unique opportunity for attendants from different parts of the world to share achievements, experiences and ideas on the important and fast advanced field of AD. As a clinician and researcher I certainly paid more attention to the development of diagnosis, drug treatment, genetics and biochemistry of AD but I would say that I was also deeply impressed by other lectures concerning non-drug treatment, especially the memory training, group care and nursing skills, the agony of family members and the ethical and legal issues.'

## USA

*Elayne Brill, Santa Barbara, California USA Alzheimer's Association*

**T**he feeling of camaraderie was everywhere. All of us were there for the same reason to share information and experiences, and to return to our respective countries better equipped to help persons coping with Alzheimer's disease and their caregivers. We also could share some lighthearted moments, for me the highlight was seeing Dr Edwin Yu of Hong Kong dancing the Hora at the closing banquet!'



# Dementia in India and China

*Bernard Inechein PhD*

*Lecturer in Public Health*

*Charing Cross and Westminster Medical School, London*

## **The prevalence of dementia**

Over 100 surveys of the prevalence of dementia have now been carried out, in many parts of the world. It is the subject of two books, and further surveys appear each year.

Despite differences in methodology, which make precise comparison very difficult, substantial numbers of sufferers have been reported almost everywhere, rising from about one per cent of people in their sixties to thirty per cent in their nineties.

Questions concerning the practical consequences include: What should be done? What should governments do? How can organisations such as Alzheimer's Disease Societies best contribute?

We are now beginning to build up a picture of dementia sufferers and their needs in the world's two largest nations, China and India. Together their populations exceed two billion.

## **Dementia in China**

Life expectancy in China is rising fast. Studies in the prevalence of dementia have a considerable history; early surveys showed very low rates, and appeared to have been methodologically defective. Recent studies report higher rates and, in the most recent of all, rates approaching those found in the West. Most studies however, have come from urban areas, and the rural peasantry and the populations of small towns have been relatively ignored. Along with rising rates has come a shift from MID (multi infarct dementia) to Alzheimer's as the age and sex composition of the demented population shifts in line with the rising age of the whole elderly population.

## **Family obligation**

Very little work has been carried out into the popular beliefs about dementia, but it is clear from at least one study in China, in the city of Guangzhou, that different manifestations of mental deterioration can be distinguished in elderly people. Family support remains strong. In 1987, 89% of Chinese people over the age of 60 lived in multi-generational households and the overwhelming majority of sick old people were cared for by relatives. Not only is ingratitude to one's parents considered morally wrong, but the obligation to provide filial care is enshrined in law.

However, several demographic trends converge to make such obligations increasingly difficult to fulfill.

## **Parents live longer**

The lengthening life-span means that more parents survive, and the likelihood grows that they will need filial support, and need it for longer. The task of care will fall to ever-ageing children. Sexagenarian children may be looking after octogenarian parents.

## **Fewer children**

As well as the additional burden through growing demand, simultaneously the supply side of caring may be weakening. The one-child family policy in China is well known. By 2030, it has been suggested, children will have fewer surviving siblings than their elderly parents. Not only will there be fewer children but ties will be weaker. Difficulties facing mothers whose only child is a girl may be particularly acute.

## **Decline of the extended family**

Good social support has been reported from one study in Wuhan to improve old people's health. But the declining power of the Chinese extended family has been widely documented. Factors include the increasing mobility of young families, the decline in the practice of inheriting jobs, and the privatisation of housing. Further weakening of support will come about if divorce among the elderly increases, although this may be offset by a decreasing hostility to remarriage.

Poverty is likely to become a major problem, especially among unsupported rural elderly. In the cities, housing is in short supply.

Homes for the elderly were reintroduced following the dissolution of the communes in the mid-1980s. They appear to provide a very varied quality of daily living and probably of care. Hospital services for patients who can be cared for at home has been in existence for over a decade. A range of domiciliary services are provided, some of which are run on co-operative or exchange principles. Increasingly, it is the elderly who care for one another.

Medical services remain poorly developed, especially in the countryside, as far as old people with dementia are concerned. Neither geriatrics nor psychiatry enjoy high status within medicine. Much mental illness in China remains stigmatised, and relatives may be inhibited from seeking help, unless problems like violence are present.

## **Perceived causes of dementia**

According to a study of Chinese Americans, dementia may be seen as result of many causes: retribution for past sins; the result of spirit possession; imbalance of yin and yang; or the consequences of hostile astrological activity. Medical help is seldom sought. One survey in Beijing found that only one per cent of a large sample of elderly people had discussed memory problems with their doctor; none of the dementia sufferers had consulted their doctor. A greater willingness to identify strokes rather than failing



memory as appropriate for medical intervention may have contributed to the pattern of apparently more MID than Alzheimer's. Chinese healers may be consulted in preference to Western-trained doctors. Help is not provided by other agencies because it is not asked for and it is not asked for because it is not considered appropriate.

### **Suicide amongst elderly**

These comments probably apply to many other countries also; but don't forget the size of the Chinese population and its influence through Chinese migrations around the world. It is unfortunate that, despite a considerable body of recent writing on mental health and illness in English on China, little has been said about the elderly. One report notes suicide as particularly prevalent among the rural elderly.

### **Dementia in India**

Less epidemiological information is available from India but recent studies are beginning to build up the picture.

The population of India is now approaching one billion, and life-expectancy may by now have exceeded 60. Psychiatric services are sparse: 3000 psychiatrists, far fewer than other mental health professionals, and 30,000 beds.

Two recent prevalence studies have been published from rural Kerala and urban and rural Madras. In Kerala the rate for dementia was 3.2% of over-60s, not far short of that reported in the West. However, adding cognitive impairment to diagnosed cases raised the figure to 5.3%. Among diagnosed cases, 58% were Alzheimer's and 41% MID. Rates were roughly similar in Madras: 2.7% (urban) and 3.5% (rural). Again using a broader criterion, adding potential to definite cases, the rates rose to 3.1% and 6.3%. Not particularly alarming rates, you may think, until you set them against the figure of India's 70 million elderly.

### **Demand for care set to rise**

Other epidemiological reports confirm the picture. Among the features of dementia in India are a

strong association with major physical illness in younger people; an absence of institutional care (all of the demented subjects in the Kerala sample were looked after at home by relatives); and a generally low standard of living, especially in rural areas. Extended family ties are weakening. However, both standards of living and life expectancy seem set to rise, and the demand for help for family carers is likely to grow very quickly indeed.

### **Lessons to be learned**

These studies contain three simple messages for Alzheimer's Disease International:

#### **1 Prevalence of dementia is similar around the world**

The proportion of the elderly population suffering from dementia is roughly similar around the world, within each age-band. It should be possible to estimate the number of dementia sufferers in each country as population statistics become available. Of course we might find areas where little dementia exists: studies of populations living in areas

of extreme climate of low population density would be especially valuable.

#### **2 Family support varies in time and from country to country**

The pattern of family support (and thus the needs of demented old people) varies from culture to culture. It varies over time too. Co-residence of elderly parents with their adult children has been declining all around the world, in both rich and poor countries. The needs of families in each culture must be mapped out carefully.

#### **3 Government help varies**

The efforts of Governments to provide help varies. The response of ADI must therefore be flexible, and this includes matters such as attempts to gain publicity and media influence. Countries whose governments display totalitarian trends may be suspicious of organisations like Alzheimer's Disease Societies, which harness the activities of individuals in ways which cut across existing subgroupings.

## Global Perspective

### **Get on the mailing list**

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### **Send us your comments**

If you have any comments or suggestions about the newsletter, or would like to submit an article – we are particularly keen to hear from carers around the world – 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 the next edition of Global Perspective. We would like to start a help column where these requests can be featured, inviting our readers worldwide to respond.

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# A growing world concern about Alzheimer's

Just a few of the members, scientists and representatives from Alzheimer's associations around the world who attended the 12th annual conference in Jerusalem



LEFT Dr Nori Graham, centre, with conference delegates from India: Dr Chandra, Dr Roy, Dr Rajkumar and Dr Gopinathan

RIGHT Michael Livni (South Africa), member of the executive of Alzheimer's Disease International (ADI); Stuart Roth (USA), Honorary Treasurer of ADI; Ed Trushke, President of US Alzheimer's Association



BELOW Mrs R Weizman, wife of the President of Israel; Brian Moss (Australia); Ruth Goldberg, Chairperson of Alzheimer's Association of Israel



ABOVE Harry Crielaars, Executive Director of Alzheimer's Netherlands; Dr James Warner (UK); Jim Jackson (Scotland), Executive Director of Alzheimer's Scotland - Action on Dementia

