





Volume 14 No.2

Global Perspective

July 2004

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

Congratulations to ADI on our 20th anniversary!

marvel at all the accomplishments and our growth. To think that we started in 1984, with only four members, and that today we are 66. How impressive!

We all know there is great power in just one person who is committed to a cause, and there are people we can each point to in history whose influence has accomplished great things for mankind. Unity is a great power; even a rope with three strands is not easily broken. How exciting are the possibilities of the unity of ADI's 66 members joined together by vision and commitment on behalf of people with dementia and their carers.

Governments must realise that 18 million worldwide have dementia. Unfortunately, that number does not give us a clear picture of this disease's influence because it does not include the carers. Governments must become creative with tangible help to carers. The financial and emotional burdens are great. Dementia puts a strain on carers that we truly have no comprehension of unless we have walked in their shoes. I am very thankful that

I was in a position to be able to keep my mother, Rita Hayworth, at home for seven years. I was able to hire around-the-clock supportive help, but what about those millions of carers who cannot? They feel so alone and are overwhelmed with this disease, both emotionally and financially. We must not close our hearts and hands to them.

There are many milestones and achievements for these past 20 years that ADI deserves recognition for, but lest I forget someone or something special, let



Princess Yasmin Aga Khan at the launch of the first World Alzheimer's Day in 1994

me just say I applaud each one of you for your accomplishments

I count it an honour to have a small part in this great team!

Princess Yasmin Aga Khan President of ADI

Dementia Forum: agenda for change



IN THIS ISSUE

 Over 150 delegates – including advocates, media, dementia experts and families from 17 European countries, USA and Canada – met in Rome at the end of June to call for greater recognition of dementia as a health care priority and create an agenda for change.

Facing Dementia: Advancing Care in Europe Forum was hosted by Eisai and Pfizer in conjunction with ADI. The Forum provided delegates with an opportunity to discuss the results

From left to right: Margarita Retuerto Buades (Spain), Sandra Skillet (UK), Maurice O'Connell (Alzheimer Europe), Maureen and James McKillop (Scotland), and Jonas Lautrop (Denmark) talked about dementia through the eyes of a person with dementia and carers

of the first pan European survey of attitudes to dementia.

The survey, commissioned by Eisai and Pfizer, showed that difficulty in recognising early symptoms, denial and fear of Alzheimer's disease, as well as

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Alzheimer's Disease International

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Send us your comments

If you have any comments about or items for the newsletter please contact the Secretariat. Articles for the next issue of Global Perspective to arrive by **15 October 2004**.

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Dementia Care in an Ageing Society

Alzheimer's Disease International's 20th anniversary conference 15-17 October 2004 Kyoto, Japan

Daily conference themes include

- future strategy of dementia care
- people with dementia and family
- dementia and human rights

All sessions will have simultaneous translation English/Japanese.

ADI and Alzheimer's Association Japan look forward to welcoming you to Kyoto.

For more information or to register contact the conference secretariat: Alzheimer's Association Japan Tel: +81 75 823 6544 Fax: +81 75 823 6545

E-mail:

adiconference@alzheimer.or.jp Web: adi2004.jtbcom.co.jp/english

Announcements and conferences

2004

9-11 September

Deutsche Alzheimer

Gesellschaft National
Conference

No time to lose! Lübeck, Germany Tel: +30 2593 7950 Fax: +30 2593 79529 Fmail:

info@deutsche-alzheimer.de Web: www.livingcongress.de/ alzheimer

17-19 September

Alzheimer's Society Annual Conference

Warwick, UK Tel: +44 20 7306 0606 Email: info@alzheimers.org.uk/ Web: www.alzheimers.org.uk/ About_our_work/AGM

15-17 October

20th International Conference of Alzheimer's Disease International

Dementia Care in an Aging Society Kyoto, Japan

Tel: +81 75 823 6544 Fax: +81 75 823 6545

Email:

adiconference@alzheimer.or.jp

Web:

adi2004.jtbcom.co.jp/english

6 November Alzheimer Society Canada Forum

A Changing Melody: A Learning and Sharing Forum for Persons With Dementia and Their Partners in Care Toronto, Canada

Tel: +1 519 888 4567, ext. 5280 Web: www.alzheimer.ca/english/ haveAD/melody04.htm

18 November

Alzheimer's Society Younger People with Dementia National Conference

London, UK Tel: +44 20 7306 0606 Email: ypwd@alzheimers.org.uk

2005

11-13 May Alzheimer's Australia National Conference

Living with Dementia –
Positive Solutions
Sydney, Australia

Email: krennie@alznsw.asn.au Web: www.alzheimers.org.au 9-12 June

15th Alzheimer Europe Conference

Dementia Matters Killarney, Ireland Tel: +353 1 622 0125 Fax: +353 1 662 0126

Email:

info@conferenceorganisers.ie Web: www.alzheimer-conference.

27-29 June

International Association of Homes & Services for the Ageing

Creative Solutions for an Ageing Society: Sharing the Wisdom Trondheim, Norway Email: iahsa@aahsa.org Web: www.aahsa.org/iahsa/ iahsaonline/Proposal

14-19 August 12th International Psychogeriatric Association Congress

Stockholm, Sweden Email: ipa@ipa-online.org Web: www.ipa-online.org

Visit www.alz.co.uk/events for more conference announcements

Editorial

Recently I was in Rome attending the Dementia Forum, cohosted by Pfizer and Eisai in conjunction with ADI. The goal of the Forum was to break down barriers and stimulate big picture thinking about the challenges dementia poses and how we (and by we I mean all organisations and individuals with an interest in dementia, not just Alzheimer associations) are going to rise to this challenge, and ensure that people with dementia and their families worldwide have access to the support and information that is available.



Elizabeth Rimmer Executive Director

We know that dementia is not high enough on the health and social agenda. We know that the majority of people affected are not coming forward to see their doctor or contact their Alzheimer associations. We know that in 25 years time health and social systems worldwide will not be equipped to provide the care and support that people with dementia and their families need unless we take action now to encourage more research and service development. We know that there is a lot that can be done now to support people with dementia and their families. We know this, but there are many who don't.

We need to share our knowledge and experience of dementia beyond the borders of our Alzheimer associations and ADI.



Carer's story

My mother's dependence scared me

Victoria Nash, Zimbabwe

must admit I never imagined I would ever take on the role of a 'carer' of anyone in my life, but as circumstances arose I saw that is exactly what I had become. My mother, known for her independence, strength and determination to accomplish in life, had suddenly lost all ability to complete a sentence. She didn't know what time of the day it was and couldn't make herself a cup of tea without taking every item out of the kitchen cupboards. My mother had become totally and utterly dependent on me - and that scared me. Who would have known I was going to become her only link with the world, as so many of her friends felt that there was no point visiting her. My mother had forgotten who

they were and that they had even visited at all!

With time I coped and adjusted to each and every aspect of the disease – from the repetition to the blank stares, and the heartwrenching moments when I left her to go to work, hoping that she would have a fulfilled day but knowing that in reality she would only look out the window, read the same line in a book over and over, or sit motionless under a tree and watch life.

Each time I became accustomed to one symptom of the disease I would be faced with another. Each moment I mourned the death of a certain aspect of her character I had always loved or admired in her earlier years. In spite of this I tried to look at the positive aspect

of being able to spend time with someone I loved and at the back of my mind I knew she loved me back, but understood that she couldn't express it or say it. I did not go through this alone. With the support of siblings, friends and our local Alzheimer association we leaned on each when we thought we could not endure another aspect of the disease.

Like everything in life and relationships, there were good and bad times, but on reflection I try to focus my memories on the good times we had and what my mother was like before she started developing Alzheimer's. I am, however, glad that I was in a position to have done my very best at giving her the best quality of life possible – and for that I am grateful.

Ronald Reagan

A courageous advocate for people with dementia

Alzheimer's Disease International pays tribute to President and Mrs Reagan for their courage in living with Alzheimer's disease. President Reagan died on 5 June at his home in California, USA.

On 5 November 1994, President Reagan bravely revealed his diagnosis to the American public, promoting greater awareness and encouraging a clearer understanding of the individuals and families that are affected by Alzheimer's disease. He ended his speech by saying 'I now begin the journey that will lead me into the sunset of my life.'

Both President and Mrs Reagan have been great advocates for people with dementia both in the USA and internationally. By speaking publicly about his diagnosis, President Reagan led the way in breaking down the stigma and myth that surrounds Alzheimer's disease. The Reagan family have been an inspiration to the millions of people around the world living with dementia, by sharing the diagnosis and the impact of Alzheimer's disease on their family.

President Reagan and Mrs
Reagan have also lent their support
to the Alzheimer's Association and
ADI. In 1983, President Reagan
designated November as National
Alzheimer's Disease Month in
the USA. The couple created the
Alzheimer's Association's Ronald
and Nancy Reagan Research
Institute in 1995. President and Mrs
Reagan also supported international
efforts to raise awareness about



Alzheimer's Association national board members gather around President Reagan as he signs the 1983 proclamation making November National Alzheimer's Disease Month in the USA

dementia by lending their support to ADI's World Alzheimer's Day™ on 21 September 1997 and 2001, highlighting the fact that dementia indiscriminately affects 18 million people worldwide.

Members' forum

Scotland/Hungary

Training carers

Alzheimer Scotland and the Hungarian Alzheimer Society recently hosted the first training programme for carers in Budapest. The first part of the course offered a 'train the trainers' programme to 25 Hungarian health care staff. This equipped the staff with practical day-to-day knowledge of caring for people with dementia, and trained them to train other health care professionals working in hospitals, nursing homes and day centres.

The second part was designed for a group of 27 carers, who were offered an insight into the philosophy and main points of Scotland's carer education programme. The aim was to provide as much knowledge and practical skills as possible in an effort to support family members who provide long-term care in the home.

The joint training played a major contribution to improving partnership between health professionals and civil organisations. It also focused the attention of the health and social system to the expected increase of people with dementia and the impact of dementia on the family in Hungary.

Sri Lanka

Recruiting volunteers

Lanka Alzheimer's Foundation (LAF) recently recruited a volunteer through Voluntary Services Overseas (VSO) – a non-profit organisation that works by placing volunteers with particular skills in organisations around the world.

The placement came about as LAF worked with a VSO programme officer on a forum for psychosocial issues. Lorraine Tamitegama from LAF said 'At the forum's conclusion, VSO agreed to consider a professional volunteer position for LAF. The formal application required an in-depth analysis of the professional expectation from the volunteer, and reciprocal service delivery plans and support available from the host. This application was submitted in October 2003.

'In December, Clare McGrory, a community psychiatric nurse, with experience of working with people with dementia, contacted VSO. Clare had the skills we were looking for and arrived in Sri Lanka in March. After following VSO's intensive six-week language and orientation course, Clare started working for us.'

Clare added 'Part of my placement involves assessing clients and going on home visits. I enjoy this part of the job the most. The relief of someone offering home support can be seen on people's face when I visit their homes. I have been to two carer support group meetings and the benefit people get from coming is evident, especially as very little is known or talked about dementia.'

For more information about VSO visit www.vso.org.uk.

■ Alzheimer University

Double first for ADI

Fifteen Alzheimer associations from Latin America gathered in Miami for a three-day training programme on leadership. The programme was run in Spanish. This is the first time ADI has run its 'Alzheimer University' training outside London and not in English.

Mariella Guerra, participant from ADI's member in Peru, said 'This training has been a great opportunity for our associations, particularly as it was run in Spanish by professional Latin American trainers. As a region, we have been limited in participating in the Alzheimer University as not everyone from our associations understands English. The facilitators helped us get the most from each session, as they really understood the realities we face back in our countries. This will definitely help us meet our associations' challenges.'

ADI realises that developing the organisational skills of its members is the first step to helping them run more effective Alzheimer associations. This is



Enna Santiago and Lillian Valcarcel, board members of Asociación de Alzheimer y Desórdenes Relacionados de Puerto Rico, put theory into practice for their association

especially crucial in Latin American and Asia, where most people in the world with dementia live.

Issues covered in the programme included volunteers, the board, strategic planning, evaluation and internal communications. A local Latin American NGO also came and talked about their organisation's challenges and how

■ Hot topic

Should Alzheimer associations provide direct care services for people with dementia?

No

Roberto Garcia, former chairman, Federación Mexicana de Alzheimer

Alzheimer associations must concentrate on educating the general public, raising awareness about the personal and social implications of the disease, providing information, developing support groups, lobbying the government to create, pass and apply the needed legislation, raising funds to support studies that can solidly back the incidence and prevalence of the disease, enforcing ethical guidelines with medical associations to dignify the person's treatment and foster the support for the family or the caregiver. The only direct service must be counselling for the families on an individual basis whenever necessary.

they overcame these to develop a successful organisation.

The workshops comprised a mixture of theory, discussion and group work, including a practical exercise using LEGO (building blocks) from which each group had to build something! The exercise demonstrated that boards must communicate, agree their objectives and delegate tasks in order to be successful. At the end of the three-day programme, participants identified three tangible objectives they would work towards over the coming year. ADI will follow their progress in six and twelve months' time.

Next year's Alzheimer University will be run in Singapore for our Asia Pacific members.

Yes

Richard Uwakwe, chairman, Alzheimer's Association of Nigeria

In developing countries, dementia services are not usually provided for by the health system. Many health professionals are not fully acquainted with the diagnosis, impact and management of dementia. True, associations are lay-oriented, but many have dementia experts on their medical and scientific panel who can provide the latest information. Volunteer workers in these associations are well trained to look after both people with dementia and carers. Alzheimer associations therefore represent rich sources of care providers.

Yes

Brian Draper, psychogeriatrician, Prince of Wales Hospital, Australia

Yes, in certain circumstances:

- Where there is a need to run a demonstration project that is fully evaluated with the intention of encouraging government and NGOs to take up the lead in a generalised way.
- Where national and other governments are prepared to fund NGOs (but not government services) for carer related services.
- In developing countries this might be the most cost effective approach.

However, there should be efforts made to ensure that any associations direct services are not in competition with other services but are run in conjunction, in partnerships.

No

Shmual Moran, executive committee member, Alzheimer's Association of Israel

5

If an association owns care facilities, it has to cope with the burden of institute management and sometimes economic decisions may surmount the professional interests of good patient treatment. In such situations the organisation will find itself acting against the interest of its own members. It is better that associations are free to represent people with dementia and their families, are able to criticise treatment in care facilities, and encourage state and private initiators to fund and develop care services.

Yes

Jim Jackson, chief executive, Alzheimer Scotland

Yes, for the following reasons:

- Hands-on experience gives Alzheimer associations credibility with government and the public.
- Services benefit people with dementia and their families (actions are better than words).
- Services help associations keep their feet on the ground.
- Starting innovatory services influences the whole pattern/quality of services. Waiting for government to act means waiting too long.
- Services raise awareness and understanding.

How and which services we provide will depend on where we are and our local circumstances. If we want to make an impact and benefit people with dementia and their families, services are a virtuous circle for development of Alzheimer associations.

AGENDA FOR CHANGE
CONTINUED FROM PAGE 1

the mistaken belief that nothing can be done about dementia, all contribute significantly to delays in seeing a doctor and ultimately receiving a diagnosis.

'The Forum elevates awareness of dementia care regionally and mobilises advocates to take action locally – two important steps toward providing people who are touched by dementia with access to the treatment, care and services that can help manage the impact of dementia on their lives,' said Elizabeth Rimmer, ADI's executive director.

The Forum provided an excellent opportunity to bring together a range of organisations and individuals with an interest in dementia, and to discuss common goals and seek solutions.

During the Forum, delegates defined an agenda for change to break down barriers, put dementia higher up the healthcare agenda and encourage people touched by dementia to come forward.

It is hoped that the Forum will act as a catalyst for change and ultimately lead to better dementia care and support, not only in Europe but worldwide.

Agenda for change

- Raise awareness of the full social, health and economic impact of dementia to make dementia a healthcare priority for governments.
- Communicate a more positive image of dementia including the value of intervention and the availability of support.
- Educate people about the early symptoms of dementia and communicate that significant memory loss is not a normal part of ageing, so as to encourage people to speak to their doctors and ensure timely diagnosis and management.

■ Living with dementia

What attitude can do

any of the phases we go through in life – such as illness, family changes and so on – end up either being positive or negative. The outcome often depends on our attitude towards the challenges that affect our life. Dealing with dementia is not easy for anyone – including the person themselves, the carer or the family. But having a healthy attitude towards the disease will help us to live a better life.

I met Frankie Mañosa about three years ago at one of our Association's activities, and to my surprise he explained to me that he had fronto-temporal dementia. My jaw dropped when I listened to Frankie - a happy and healthy looking man ready to help with whatever needed to be done on the day. The way Frankie explained his disease, his feelings, his outlook on life and his future plans really surprised me. This is a man who received a diagnosis and, instead of being afraid, became informed about his illness and retained his positive attitude. No matter what happens, he is alive and enjoys life with all its challenges. His wife Dorita, whom I always call his guardian angel, also surprised me with her energy and willingness to take care of Frankie and his

needs, as well as to help other people with dementia and their families. What I see in this couple is a healthy attitude towards a disease. An attitude of being together through this challenge, helping others to accept what can't be changed, but demonstrating that still there are many things that can be done to live a better life.

Frankie is an advocate on our board of directors - a voice for people with dementia. He brings us another part of the story. We, health professionals, have the knowledge and the skills to assist people with dementia, family and carers to cope with dementia, but Frankie has the experience of the disease. When he speaks, you can sense his feelings, his challenges, his memory fading away which he fights like a knight, using reminders, hints, anything that will help him to stay active and to help others. A beautiful example of staying alive and productive, no matter what is affecting you. A healthy attitude that brings them support as they bring support to others. An example to emulate.

Enna Santiago, President of Asociación de Alzheimer y Desórdenes Relacionados de Puerto Rico

21 September · World Alzheimer's Day™

No time to lose

Alzheimer associations around the world are finalising their plans to mark World Alzheimer's Day on 21 September. Central to this year's campaign is the involvement of people with dementia. Members have been encouraged to organise an event in their capital or a symbolic city in their country in which there will be significant gathering of people with dementia and their carers. Materials have been printed in 20 languages to help members get the 'No time to lose' message out.

ADI will be hosting its own event with a reception in London at the Houses of Parliament where guests will include people with dementia, carers, and high commissioners and ambassadors of each of our 66 member countries. In addition, ADI will be writing to all the world's governments to remind them that the number of people with dementia is set to double over the next 25 years, as populations and life expectancy continue to increase. There is no time to lose.



■ Research update

Links with diabetes

Women with type 2 diabetes may experience greater cognitive decline than women without diabetes, and may have worse cognitive function, according to a study by researchers from Boston, USA, published online by the *British Medical Journal* in February. Cognitive assessments of thousands of women who had been registered nurses were performed by phone. Women with type 2 diabetes performed worse on all cognitive tests than women without diabetes.

Separate research at the Rush University Medical Centre in Chicago, USA, reported on a large longitudinal study, which demonstrated an increased risk of Alzheimer's disease in people with diabetes. This adds to several previous studies suggesting a connection.

http://bmj.bmjjournals.com/cgi/content/abstract/bmj.37977.495729.EEv2?ecoll

http://archneur.ama-assn.org/cgi/content/abstract/61/5/661

New link found to mutant protein

Scientists in New Zealand have made a new connection between a mutant protein, similar to one known to cause Huntingdon's disease, and Alzheimer's disease.

Alzheimer's disease is known to be associated with a build up of the beta amyloid protein. Researchers at the University of Auckland found that a mutated version of another protein, known as TBP, also accumulates in the brains of people with Alzheimer's disease.

Dr Steven DeKosky, chairman of ADI's medical and scientific panel, commented 'This very interesting finding will require confirmation by other groups, but if confirmed will be a very interesting new development: yet another misfolded protein contributing to neurodegenerative diseases. We will watch with great interest how exploring this abnormality may explain the genesis or development of the pathology of Alzheimer's disease, and what may be needed to combat it.'

The researchers are now seeking funding to take the research to the next stage of determining if the

protein is a contributing factor in Alzheimer's disease.

http://dx.doi.org/10.1016/j.molbrainres.2004.03.018

Curry may offer protection

A new study has found that a compound found in turmeric, a yellow spice often used in making curries, could be an effective enhancer of an enzyme that protects the brain against degenerative brain disease. The compound, curcumin, is known to have both antioxidant and anti-inflammatory properties.

The researchers from New York Medical College, USA and the University of Catania in Italy presented their findings at an annual scientific conference held by the American Physiological Society.

Dr DeKosky commented 'This is one of a number of compounds with biological activities that might be beneficial in treatment or prevention of Alzheimer's disease. Interestingly, lower rates of dementia occur in India; while there are several potential explanations for that finding, consumption of curry by the population studied might be a contributor. However, it will take prospective studies to prove the effectiveness.'

http://www.the-aps.org/press/conference/eb04/13.htm

Raising awareness



Reaching out to today's children and teaching them about dementia creates an important foundation for our future support. It also helps children and young people cope when a relative has dementia. So what initiatives have Alzheimer associations developed to do this?

Singapore. Over 1000 students helped raise funds at the association's Memory Walk in 2003

Providing information through books (such *The Smell of Chocolate* by Alzheimer's Australia WA), factsheets (such as *Explaining to children* by Alzheimer Society of Ireland) and websites (such as Alzheimer's Association Japan's www.alzheimer.or.jp/kodomo) is the first step many associations have taken. Competitions are also a popular way of engaging children. Hong Kong Alzheimer's Disease Association recently launched an essay competition for high school students.

Awareness days or weeks have also been used and this year the Alzheimer's Society has dedicated theirs to children. The information pack accompanying the campaign includes a video, which can be viewed at www.alzheimers.org.uk.

More and more associations are now working directly with schools. Alzheimer's Australia SA, with support from a local foundation, offered a scholarship to primary and high school students throughout the state that would assist community awareness of memory loss. The project was so successful the foundation agreed to support it again. Contact alzsa@alzheimerssa. asn.au for more information.

In September 2002, Alzheimer Scotland piloted a Dementia Friendly Schools Adventure scheme. Children were told about dementia, why people develop it and what happens when they do. The children were encouraged to think about memory and how life would be without it. They were then given an exercise which attempted to make them confused and asked how this made them feel. Their responses were then compared to what a person with dementia might experience.

Singapore's Alzheimer's Disease Association (ADA) initiated a different approach to reaching students by tapping on them as a source of volunteers by engaging them in befriending, organising activities such as outings and games, providing entertainment (singing and dancing) as well as helping out during meals, exercise and activity sessions.

Students also help out at fundraising events such as Memory Walk.

In a similar fashion, Alzheimer's Australia WA invited local high school students to participate in their annual tea dance by preparing and serving food at the event. Students learnt about dementia and diabetes, how they affect people and what sort of food is most suitable for people these conditions. On the day, guests invited the students to dance! The day was a great success. Guests enjoyed a day out whilst students learnt and experienced a positive interaction with people with dementia.

In some countries, dementia has been integrated into the school curriculum. Alzheimer's Australia Vic has worked with their Education Department in the 'Health and Physical Education' learning area of the curriculum. The 'Self and Relationships Strand' of this learning area identifies the major stages of development across the human lifespan. Learning takes place through four levels of stories and activities. The stories are underpinned by the physical and cognitive changes that occur with ageing. Although dementia is not mentioned until level four, students learn about the changes that occur with dementia. For more details on this initiative contact gglazebrook@alzvic.asn.au

ADA in Singapore is also able to reach out to schools through the Community Involvement Programme (CIP) launched by the Ministry of Education. Under the CIP, every student from primary to junior college is involved in providing a minimum of six compulsory hours of community service a year.

As the number of people with dementia continues to rise, everyone needs to know about dementia. All our associations have a role to play in getting the message out. Only then can we promote greater understanding and help everyone – whatever their age – deal with the impact of dementia.