



Alzheimer's Disease
International

June 2013
Volume 23 No. 2

Global Perspective

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

28th International Conference of Alzheimer's Disease International Action for Global Change

ADI partnered with TADA Chinese Taipei to host the 28th International Conference of Alzheimer's Disease International in Taipei from 18 to 20 April. More than 1000 delegates, including people with dementia, professional and family carers, researchers, clinicians, scientists and staff of national Alzheimer associations, gathered in the vibrant city to exchange knowledge and experiences through informative sessions and lively workshops.

Under the title *Dementia: Action for Global Change*, the conference featured plenary sessions on topics such as quality of life for people with dementia and carers, challenges for the global health system and prevention and risk factors in dementia. Keynote speakers included Dr Akira Homma from Japan, Dr Peter Foltyn from Australia and Sandrine Andrieu from France.

Workshops, hosted by ADI to assist the strengthening of Alzheimer associations worldwide, covered various subjects including fundraising, managing and establishing association branches, and how ADI members can make dementia a global health priority through local action.

People with dementia played a large role in the conference with a strong delegation from Japan present and an inspiring Opening Ceremony dance performance from Hsieh Pao-Tsai Yang and Shang Chih Yang from Taipei. A session organised by and featuring people with dementia from Japan, Australia, Czech Republic, Indonesia and the UK provided a unique insight into their day-to-day lives and favourite activities.



Hsieh Pao-Tsai Yang, who is living with dementia, performed with her husband Dr Yang during the Opening Ceremony

The winners of the 1st ADI-MetLife Foundation Awards for best dementia care education projects (see page 7) were presented during a picturesque conference dinner on the 86th floor of the city's landmark Taipei 101.

A busy exhibition and poster presentation area brought together the local and international delegates to share their thoughts on their new knowledge and to make connections. Alzheimer's Disease Chinese were presented with the award for the best exhibition stand based on votes from conference delegates.

ADI would like to thank TADA Chinese Taipei for all of their hard work towards making the conference a great success.

MORE CONFERENCE NEWS ON PAGE 17

UK government leads on global action

On 15 May, the UK government announced their commitment to establishing global collaboration on dementia research in order to address the rising numbers of people living with dementia and the strain it places on health care systems worldwide.

Prime Minister David Cameron plans to use the UK's Presidency of the G8 to launch his campaign for a new approach on dementia, including it on the agenda of a G8 meeting in June and hosting a dementia summit in London later in the year. He will also work with the USA government

to identify potential areas for development in dementia research and treatment.

ADI welcomes this very important step towards global coordination and applauds the UK government on their decision to take the lead in addressing this vital issue.



Alzheimer's Disease International

The views stated in Global Perspective are personal and do not necessarily reflect the views of ADI. Published by Alzheimer's Disease International, London, United Kingdom. Editor: Sarah Smith. Design: Julian Howell. Printed by Maygray Graphics Ltd. Copyright © Alzheimer's Disease International. All rights reserved. ADI is a not for profit organisation registered in the State of Illinois, USA.

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 26 July 2013.

Secretariat

Alzheimer's Disease International
64 Great Suffolk Street
London
SE1 0BL
Tel: +44 (0)20 7981 0880
Fax: +44 (0)20 7928 2357
Email: info@alz.co.uk
Web: www.alz.co.uk

Join us on
Facebook and Twitter



www.facebook.com/alzheimersdiseaseinternational



www.twitter.com/AlzDisInt

Editorial

Jacob Roy, Chairman



Successful conferences should be the beginning of bigger things. ADI's conference in Taipei was unique in many ways. Everything about the conference worked out with clockwork precision. This is the outcome of the hard work put in by our host, TADA Chinese Taipei. The warmth of the local people and generous hospitality has left an indelible mark in the minds of all participants. To top it all, the International Memory Walk, led by the President of Taiwan, sent a clear message of dementia care to the general public. I am sure that the Taiwanese government will soon introduce its national dementia plan.

In the month of May, we had the second African regional meeting of ADI which was jointly organised with Africa Alzheimer Congress in Johannesburg, South Africa. This was another well-organised and well-attended event. Here we came across the perception of dementia as possession or some kind of black magic as believed by a number of people in Africa. So, while we use science and technology to address this tragic illness, in some other parts of the world local belief makes them see dementia differently. Thus the challenge of raising global awareness remains formidable.

At the World Health Assembly in Geneva, we continued our efforts in mobilising support for pushing dementia forward as one of the five important non-communicable diseases (NCDs). We need to work vigorously to muster the support of the world's governments. This is where we are looking to our member associations to push the dementia cause forward with their respective governments. In May, it was extremely encouraging to hear that the UK government plans to lead the call for global collaboration on dementia research, beginning with the G8 meeting this year. We hope that many more governments will choose to follow their lead.

Events

13 – 18 July 2013

Alzheimer's Association International Conference

Boston, USA
Email: aaic@alz.org
Web: www.alz.org/aaic

10 – 12 October 2013

23rd Alzheimer Europe Conference

Valleta, Malta
Web: www.alzheimer-europe.org/EN/Conferences

16 – 19 October 2013

VII Congreso Iberoamericano de Alzheimer/ XI Reunión de Asociaciones de Alzheimer de Iberoamérica

Montevideo, Uruguay
Web: www.audas.org.uy

17 – 20 October 2013

8th International Congress on Vascular Dementia

Athens, Greece
Email: vascular_dementia@kenes.com
Web: www.kenes.com/vascular

14 – 16 November 2013

6th Clinical Trials Conference on Alzheimer's Disease

San Diego, USA
Email: ctad@ant-congres.com
Web: www.ctad.fr

11 – 14 December 2013

16th Asia Pacific Regional Conference of Alzheimer's Disease International

Hong Kong SAR and Macau SAR
Email: headoffice@hkada.org.hk
Web: www.aprc2013-hongkong-macau.com

26 – 29 March 2014

13th International Geneva/Springfield Symposium on Advances in Alzheimer Therapy

Geneva, Switzerland
Tel: +1 217 545 7711
Email: ahamilton@siumed.edu
Web: www.siumed.edu/cme/alzheimer

1 – 4 May 2014

29th Annual International Conference of Alzheimer's Disease International

San Juan, Puerto Rico
Email: adi2014@mci-group.com
Web: www.adi2014.org

Members' forum

ADI members: do you have news you would like to share with the global dementia community? Please contact us

AFRICA

2nd Regional Conference

ADI staff, members and new association representatives at the regional meeting



ADI members within the African region met in Johannesburg, South Africa in May for the 2nd Africa Regional Conference of ADI and the 1st Africa Alzheimer's Congress. The meeting provided ADI staff with details of the incredible challenges that Alzheimer association in Africa are facing, particularly relating to stigma.

The first day of the conference was open to carers and medical professionals, with the second day targeted specifically at those with a medical profession. A members meeting enabled associations to share their challenges and concerns and ways in which ADI could assist were discussed. These talks are ongoing and arrangements are

already being made to ensure better communication between associations within the region and the ADI office. The beginnings of a Dementia Manifesto for South Africa were discussed at the conference with the intention of its use within campaigns aimed at the country's government.

BARBADOS

New tracking device for Barbados

On 29 April, Barbados Alzheimer's Association launched a tracking device in partnership with the Royal Barbados Police Force. The device will be used to help carers locate people living with dementia.

Present at the well-attended launch event was the Minister of Health who offered his support of this new initiative and commended the association for their hard work. Debbie Benczkowski from the Alzheimer Society of Canada was also present alongside Norma Inniss, President of the Alzheimer's Association of Trinidad and Tobago.



The tracking device being presented at the event

MEMBERS' FORUM CONTINUED

FINLAND**Brain Awareness Week***The Alzheimer Society of Finland*

The Alzheimer Society of Finland and its member associations celebrated the international Brain Awareness Week in March this year with the theme *Exercise for Your Memory!*

The week consisted of events all over Finland. We brought the joyful message of maintaining one's brain health through one's own action and physical activity. Exercise is the perfect way to keep mind, body and memory fit!

The *Exercise for Your Memory!* campaign lasted from September 2012 (World Alzheimer's Day and Finnish Memory Week) to Brain Awareness Week 2013. The campaign used social media which hopefully brought new – and younger – people knowledge of the Society and its activities.

The *Exercise for Your Memory!* campaign was launched at HeiaHeia.com, a social web service that lets people keep a training log, as well as share activities with others. It is available in multiple languages, including English. HeiaHeia.com is used by individuals from over 140 countries, representing a broad range of ages and activity profiles. The feedback proves that people are genuinely seeing results: increasing their physical activity, losing weight, and improving their health.

During our six campaign months we collected over 30,000 active hours in HeiaHeia.com, which means that our campaign participants were physically very active for their memory!

We urged people to take care of themselves and thus decrease their risk of getting Alzheimer's and other memory related diseases. Though we do not know for certain who gets the disease, the studies show that we can at least push the disease further back in time and age. Exercise brings great benefits to us all, no matter what your age or condition is. Also

people with memory related diseases can maintain their physical, social and cognitive health through exercise. We want to bring forward a positive message instead of scaring people with risks. We know better nowadays!

For more information visit www.muistiliitto.fi/eng

LEBANON**Promoting early diagnosis**

Alzheimer's Association Lebanon, in collaboration with the country's Ministry of Social Affairs, implemented its first Alzheimer's disease early diagnosis session in Nabatieh (South Lebanon) on 30 May. The session was sponsored by Lundbeck pharmaceuticals.

The session targeted 74 elderly people over the age of 64 living in Nabatieh and its surrounding villages.

Those in attendance underwent a first assessment examination by two expert occupational therapists and 32 cases were then referred to a neurologist for the second phase of diagnosis.

The results were as follows:

- 16 cases of Alzheimer's
- 6 cases of depression
- 8 cases of potential Alzheimer's which need to follow-up with the doctor at his clinic

The diagnosed people with dementia received drug treatment samples as per the doctor's coordination.

The session reaped great success especially in terms of the attention the elderly paid to their health and their desire for an early diagnosis. Alzheimer's Association Lebanon will follow-up with all the diagnosed people with dementia and help their carers with the management of the disease.

A further six diagnosis sessions will be taking place this year across the county, with the second scheduled for 4 July.

For more information visit www.alzlebanon.org

MEXICO**Successful national conference**

ADI's Director of Development Johan Vos joined more than 1,000 delegates in May for the XVIII Congreso Nacional de Alzheimer. The event, hosted by Federación Mexicana de Alzheimer (FEDMA) in Monterrey, received widespread media promotion of its varied and impressive programme.

During the conference a meeting with health officials took place to discuss the future possibility of a national dementia plan. FEDMA now hopes, ahead of their next conference, to build upon the developments from this event and looks forward to greater awareness within the country's government and further steps towards the creation of a dementia strategy.

For more information about the work of FEDMA visit <http://fedma.org.mx>

PERU**1st Latin America national plan confirmed**

Daisy Acosta, Martin Prince, Mariella Guerra and Roberto Ventura with Congressman Urtecho (front) during the visit in March

On 13 May, a law was passed by the Peruvian government that confirmed the development of a national dementia plan for the country. The responsibility was then passed to the Ministry of Health to prepare the plan within a 90 day period.

In March, ADI Honorary Vice President Daisy Acosta joined Martin Prince, coordinator of the 10/66 Dementia Research Group, and Roberto Ventura from Uruguay in a visit to Congressman Urtecho who has backed the development of the plan and moved the process forward in recent months.

This important development marks a great success for Asociación Peruana de Enfermedad de Alzheimer y otras Demencias (APEAD) after their on-going campaign to call political attention to the issue.

For more information about APEAD visit www.alzheimerperu.org

SCOTLAND

Second national plan launched

Alzheimer Scotland supported the Scottish government on the

introduction of its second National Dementia Strategy on 3 June.

The Strategy, which will run until 2016, highlights three main challenges that the plan hopes to address including: promoting quality of life and wellbeing through support and care of people with dementia and their carers, improving services and support throughout the course of dementia, and the delivery of services in an efficient and effective way to address the increase in the number of people with dementia in Scotland.

Successes from the previous Strategy include an increase in diagnosis rates, the training of 300 Dementia Champions, and the appointment of Alzheimer Scotland Dementia Nurse Consultants to health Boards across Scotland.

To view the *Scottish National Dementia Strategy 2013-2016* visit

www.scotland.gov.uk/Topics/Health/Services/Mental-Health/Dementia

SPAIN

Cities of Solidarity with Dementia

CEAFA announced in May that almost 200 towns in Spain have now joined the Ciudad Solidaria con el Alzheimer (City of Solidarity with Dementia) programme during its first year. It is believed that these towns represent just over 13% of the Spanish population.

The campaign began in May 2012 with Navarra becoming the first Ciudad Solidaria con el Alzheimer with the opening of its Caregivers Park. In addition, 29 institutions and companies have joined the entidades solidarias (solidarity organisations) project.

For more information visit lamemoriaeselcamino.com/ciudad-solidaria-con-el-alzheimer

Dementia newsflash

■ Bangladesh



Frank Schaper with ASB volunteers

The Alzheimer Society of Bangladesh (ASB) received a visit from Frank Schaper, former CEO of Alzheimer's Australia WA, at the end of May. After visiting the Society's office in Dhaka, he laid the foundation stone of a new dementia service and information centre in Thakurgaon.

■ India

ARDSI has formed a new chapter in Mysore. The chapter becomes the 20th in India and the second chapter in Karnataka. ARDSI Mysore currently has thirty two members and aims to identify people with dementia as well as training medical professionals.

■ Mauritius

On 12 June, Association Alzheimer Mauritius marked the launch of their new website at an event attended by the Vice President of Mauritius, H.E. Mrs Monique Ohsan Agnes Bellepeau. The new site can be found at www.alzheimer.mu

■ Sri Lanka

On 28th February, Lanka Alzheimer's Foundation launched a new publication, General Assessment Manual – Guidance on how to conduct a psychosocial assessment, produced in collaboration with Volunteer Services Overseas in Sri

Lanka. The manual acts as a reference and training tool for health professionals on how to interview and support those seeking help.

■ New associations

ADI was pleased to come into contact with two new Alzheimer associations earlier this year

Dementia Namibia attended the recent Africa regional conference (see page 3) and shared their experience of running an association in Africa (see page 13).

The AIQadri Foundation for Alzheimer's and Development in Yemen was established on 2 May in the presence of representatives from the Ministry of Social Affairs and the Ministry of Public Health. ADI hopes to maintain contact with both associations as they grow.

Member profile

Alzheimer's Australia

Dementia moves out of the shadows

Glenn Rees AM, CEO Alzheimer's Australia



Over the past three years, Alzheimer's Australia has adopted a much higher profile in its advocacy to improve the support and care for the more than 320,000 Australians with dementia and their 1.2 million family carers.

To achieve change we created the *Fight Dementia Campaign*. Over the past two years, the campaign has seen 500 people marching on Parliament House and we have reached millions of Australians on a number of occasions with our messages through conventional and social media. We have sent Valentine's Day cards to Parliamentarians asking them what they would do if their loved one couldn't remember them. We now have almost 50 federal Parliamentarians signed up as dementia champions.

**FIGHT ALZHEIMER'S
SAVE AUSTRALIA**
FIGHTDEMENTIA.ORG.AU

The campaign has achieved outcomes. Last year the Government committed to tackling dementia in the *Living Longer, Living Better* aged care reform package with \$270 million over five years. As part of the package Australian Health Ministers agreed to make dementia a National Health Priority Area alongside other major diseases including cancer and heart disease. Significantly for the first time in national Australian health policy initiatives are being taken to achieve timely diagnosis and improved care in hospitals for people with dementia.

In Australia, as in other countries, there have been many reports that document the stigma and discrimination experienced by people with dementia. We believe that to shift community attitudes, we need to engage the wider society in social action and engagement

with people with dementia. To promote these ideas we have released two publications: *Dementia Friendly Societies: The Way Forward* and *Cognitive Impairment Symbol: Creating Dementia Friendly Organisations*, that outline ways to make our society more dementia-friendly.

Many communities in Australia are already doing wonderful things to promote social inclusion. There are dementia choirs, memory cafes, walking groups and countless other activities. Alzheimer's Australia has developed education resources for community organisations, with the *Is It Dementia?* online training package (www.isitdementia.com.au). But there is no national approach to recognising communities for their good work or for promoting others to take up these approaches.

In doing this work we have drawn on the good work done in the UK and Belgium on dementia-friendly societies – it seems many of us are thinking the same way!

As well as dementia-friendly societies, there is a need for dementia-friendly organisations. Organisations such as Centrelink, banks and financial institutions, retailers and hospitals could become dementia-friendly with training and education for staff.

The concept is that organisations who sign up to be dementia-friendly display a symbol to indicate that they have trained staff able to provide a dementia-friendly service. It is, of course, up to the individual whether to make use of the service, and there is no question of the individual themselves wearing the symbol.

By creating a society that is dementia-friendly, we hope to reduce the negative attitudes towards people with the chronic disease. People with dementia are, first and foremost, human beings and should not be defined by their condition.

Developing a programme to encourage dementia friendly communities and organisations only makes sense if it is done in collaboration with people with dementia. We will be working closely with our national consumer advisory groups. This includes the new dementia advisory group, which will be made up of people with dementia, on the development of resources and guidelines.

Lastly we have continued to advocate vigorously for increased Government funding for research. There has been some increase but not at the level we believe is necessary. However, a boost to funding for research has resulted from the selflessness of Hazel Hawke, first wife of former Australian Prime Minister Bob Hawke, in speaking out about her diagnosis of dementia and creating the Hazel Hawke Alzheimer's Research and Care Fund.

We owe a deep debt to Hazel Hawke and her courage in disclosing her diagnosis – she remains the only prominent figure in Australia to have done so – which perhaps says a lot about the stigma that continues to attach to dementia.

ADI would like to congratulate Alzheimer's Australia's Chief Executive Officer, Glenn Rees, on being named a Member in the General Division of the Order of Australia for his significant service to community health in the Queen's Birthday List in June.

Congratulations also go to Henry Brodaty for being chosen to receive the Lifetime Alzheimer's Australia Award in May in recognition of his long-standing commitment to improving the quality of life for people with dementia.

■ 1st ADI-MetLife Foundation Awards

Awards highlight global creativity in dementia care education

In December 2012, ADI, with the support of MetLife Foundation, announced the first set of awards for the Best Dementia Care Education Projects. Applications were accepted under three world region categories: the Americas, Asia Pacific, and Europe, the Middle East and North Africa. Each award was worth a total of US\$10,000.

A total of 20 applications were received from national Alzheimer associations worldwide: 5 for the Americas category, 9 from the Asia Pacific, and 6 from Europe, the Middle East and Africa.

Applications were reviewed and judged by a jury made up of Prof Henry Brodaty from Australia,

Lynda Hogg who is living with dementia in Scotland, Dr Daisy Acosta from the Dominican Republic, ADI Chairman Dr Jacob Roy, Dale Goldhawk a former carer from Canada, Dr Richard Uwakwe from Nigeria, and ADI Executive Director Marc Wortmann.

The applications received for the award highlighted the impressive efforts going into raise awareness of dementia care within the general public, with medical professionals and family carers.

In this issue of *Global Perspective* we celebrate the associations that entered their projects and their hard work to address the lack of awareness.

WINNERS AND RUNNERS UP

THE AMERICAS

WINNER

Asociación de Lucha contra el Mal de Alzheimer (Argentina)

PROJECT TITLE

Education and Training for Coordinators of Support Groups for Family Carers of People with Alzheimer's and Other Dementias

The purpose of the project was to offer guidance and training to those volunteers who either play or intend to play the role of Coordinators of Family Support Groups. Through interactive sessions – including role play, case studies, and group work – the programme provided the elements needed for the role. When the programme took place in November 2011, 71 people enrolled from 27 cities in Argentina. The programme was a great success, gaining ALMA great recognition, and secured its future in the country.



RUNNER UP

Asociación de Alzheimer de Puerto Rico

PROJECT TITLE

The School for Informal Family Caregivers of Persons with Alzheimer's Disease

In collaboration with three nationally recognised universities, the association developed this project for unpaid family carers based on the knowledge of carers' needs established through their programmes. The project, which began in 2011, consisted of 8 sessions per school quarter for groups of up to 35 people. The project provided training on the basics of dementia, strategies to provide safe care at home, skills to manage communication and behavioural changes, preventing medical complications and advice on self-care. Feedback on the project gathered in 2012 reported the level of satisfaction from carers at 92%.

CONTINUED

■ 1st ADI-MetLife Foundation Awards CONTINUED

ASIA PACIFIC

WINNER

Alzheimer's and Related Disorders Society of India

PROJECT TITLE

Making Cochin a Dementia-Friendly Community – An ARDSI Approach

ARDSI's project, which aimed to raise public awareness of dementia by targeting different groups, took place throughout 2011 and 2012. Activities included awareness programmes for school children, dementia care tasters for student practitioners and skills training for care home staff. The programme received strong feedback from participants and is a good example of a model that is easily transferable to other countries.



RUNNER UP

Alzheimer's Australia NSW

PROJECT TITLE

DementiaCare: E-learning Resource and Training Network

Since its creation in 2007 the programme has been improving clinicians' knowledge and understanding of providing support to people with dementia and their carers. The online course, which is aimed at New South Wales healthcare staff working in metropolitan, rural and remote areas, is free of charge and is available 24 hours a day. As well as the course, the resource also features forums and online chats. By the end of 2012 more than 800 clinicians had been trained across New South Wales.



EUROPE, MIDDLE EAST AND AFRICA

WINNER

Alzheimer Association Lebanon

PROJECT TITLE

Capacity Building & Outreach Program

Alongside the Ministry of Social Affairs, Alzheimer's Association Lebanon aimed to reach those living in rural and poorer urban communities with their project and to increase services to them. Through the Ministry's 130 Community Development Centres a series of one-day training sessions took place for health and social workers, led by dementia experts including doctors, occupational therapists and social workers. Follow-up outreach also took place to raise awareness among families and carers. Since the project was introduced by Diane Mansour, an estimated total of 800 individuals across the country have directly benefitted from the programme.



RUNNER UP

Iran Alzheimer Association

PROJECT TITLE

Dementia Awareness and Education Project for Elementary 5th Graders and Families

After two years of negotiation with the Education Board of Tehran Province, the project was finally introduced in 44 elementary schools in September 2011. With the aim of increasing children's awareness of dementia, 6 hours of training was delivered over a two-week period highlighting the relationship between children and dementia and the need to raise awareness. After the training was complete 4500 pupils received an educational package which included an evaluation questionnaire of which 1554 were returned. Results from the questionnaires showed that 70% had shown an increased interest in dementia.

MORE APPLICATIONS

THE AMERICAS

ASSOCIATION
APAZ (Brazil)

PROJECT TITLE
'To know for living with' – information about Alzheimer's disease for children and teenagers

The project started in 2006 with the development of a handbook for young people as well as a series of other tools to raise awareness of dementia. Five thousand handbooks were printed, with a further 30,000 produced in 2012. The handbook has been distributed on a daily basis from APAZ's headquarters and, in September 2012, APAZ representatives travelled by subway to more remote locations and offered a handbook to every passenger. The project is now being replicated in Trinidad and Tobago.

ASSOCIATION
ABRAZ (Brazil)

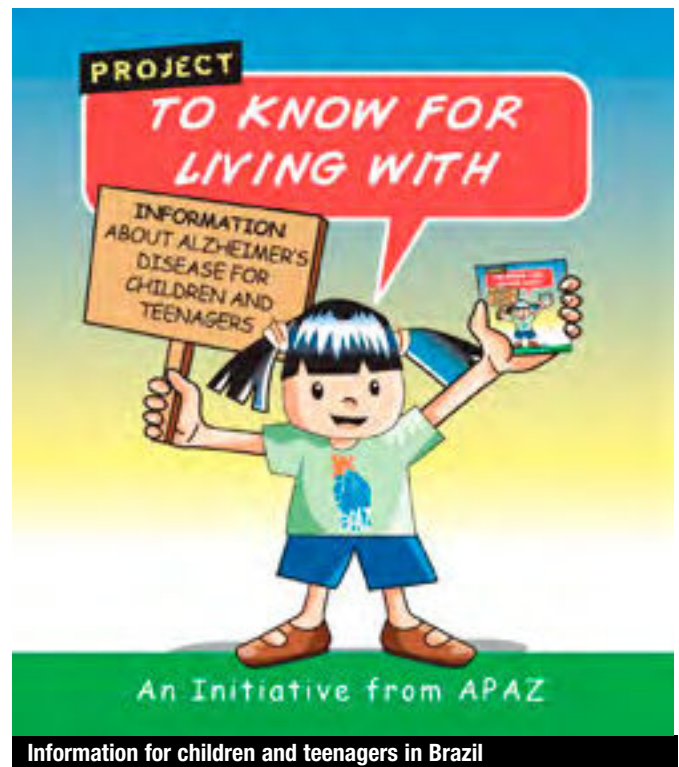
PROJECT TITLE
Classification, standardization of procedures and training coordinators of 97 support groups for family caregivers of Alzheimer's Disease in Brazil

To create a set of procedures for monitoring 97 support groups across Brazil, ABRAZ worked with existing coordinators to establish a classification system and procedural manual. Based on each group's objectives, classification included informative groups, socialization groups, psychological support and mixed groups. The procedural manual aims to standardize the methods of running a group with advice to coordinators on conducting the different categories of groups.

ASSOCIATION
Asociación Costarricense de Alzheimer y otras Demencias (Costa Rica)

PROJECT TITLE
Campaña Nacional para el diagnóstico temprano de la Demencias en Costa Rica

A national campaign was developed to educate the country's population about early recognition and diagnosis. Television commercials, media interviews and short videos were used to reach the public with further dissemination through social media. The campaign, which ran from 2011 to 2012, is believed to have reached close to 90% of the population.



ASIA PACIFIC

ASSOCIATION
Alzheimer's Australia Tas

PROJECT TITLE
Changing the world of persons living with dementia through a rehabilitative approach to care

This project was developed to introduce a rehabilitative person-centred model of care for residents living in a 15-bed secure dementia/memory support unit. The programme, which took place over a 16-month period until October 2012, provided information through face-to-face education sessions as well as on-going mentoring and support for all staff. The emphasis of the project was on developing an inclusive homelike environment and visits from government officials have led to the promotion of the unit as an example of better practice in dementia care.

ASSOCIATION
Alzheimer's Australia Vic

PROJECT TITLE
8 things you need to know about dementia: A dementia education resource for Culturally and Linguistically Diverse Communities

Alzheimer's Australia Vic developed this education resource to meet the needs of culturally and linguistically diverse communities, providing them with general information about dementia as well as sign-posting to local and national services available to them. Since its initial launch in Greek and Italian, the booklets accompanying the presentation – given

■ 1st ADI-MetLife Foundation Awards CONTINUED

by a training facilitator – are now available in Cantonese, Mandarin, Spanish, Turkish and Vietnamese. The project has since become national, being used by Alzheimer's Australia staff in each State and Territory.

ASSOCIATION

Alzheimer's Australia Vic

PROJECT TITLE

Dementia Care Essentials for Aged Care Workers

With the aim of assisting those caring for people with dementia in residential and community aged care, Alzheimer's Australia Vic introduced this competency-based accredited training system. The programme includes training on good communication and planning, effective strategies for managing people with dementia, appropriate activities for people with dementia, and different methods for understanding and responding to behavioural issues. The three-day workshops have also been popular among other staff in residential care facilities and government funding for the training has been continuously renewed since 2006.

ASSOCIATION

Alzheimer's Disease Chinese

PROJECT TITLE

Capacity-building for clinical diagnosis, care management of dementia

Alzheimer's Disease Chinese developed this large-scale education programme to target a number of groups to improve their awareness of dementia and dementia care. Their tailored training for health professionals was offered to memory specialists and general practitioners, case managers, and community health doctors. Almost 700 memory specialists, 1000 physicians and 200 nurses received the training. Their education to the general public included a national campaign co-sponsored by China Central Television (CCTV) and education for journalists. Training was also provided for dementia carers at a monthly support group meeting and a manual, *Smart Caregiver*, was produced.

ASSOCIATION

Alzheimer's Disease Association Singapore

PROJECT TITLE

Eldersit Respite Care Service

Implemented in early 2011, the Eldersit service combined respite for carers with therapeutic, cognitively stimulating activities for people with dementia. Activities for people with dementia would be based on their individual interests and would be coordinated one-on-one by a trained Eldersitter. Feedback from the first phase of the programme showed that 83% of carers had noticed an improvement in their own mental health and well-being. Results from the second phase showed improved well-being in 100% of the carers.

ASSOCIATION

Lanka Alzheimer's Foundation

PROJECT TITLE

The Maradana Project

This community dementia care project was introduced in May 2012 to provide information about dementia to households and residents within a small community in Maradana, one of the poorest areas of Colombo. Around 40 home visits were carried out from October to December 2012 with information being shared and simple, holistic assessments being made of those showing signs of dementia. In addition, materials were prepared in Sinhalese, Tamil and English for distribution during an awareness campaign at the local temple.

ASSOCIATION

The Alzheimer's and Related Disorders Association – Thailand

PROJECT TITLE

Sunday dementia caregiver support group

Established 10 years ago, this monthly support group enables carers and people with dementia to learn from each other's experiences as well as being offered information on a range of dementia-related topics. The 3-hour meetings, which usually comprise of 15 to 20 participants, are divided into two sections: emotional support and lecture session. Participants usually attend the group sessions for 6–12 months. This has also proven to be a useful tool for others who wish to host their own support group elsewhere in the country.

EUROPE, MIDDLE EAST AND AFRICA

ASSOCIATION

Fondation Compassion Alzheimer Bulgaria

PROJECT TITLE

'I exist. I am here.' – Pilot training for dementia caregivers in Bulgaria

In 2012, Fondation Compassion Alzheimer Bulgaria organised and conducted, together with experts from St Andrews University in Scotland, a pilot training programme for dementia carers in residential homes. The focus of the training was on developing the carers' skills and knowledge to enable them to provide specialised and person-centred care. Around 40 carers were trained as part of the programme and the positive effects have been presented to the national authorities.

ASSOCIATION**Cyprus Alzheimer Association****PROJECT TITLE****'DI-MENTIA' A New Musical**

Commissioned by UNESCO to develop a live performance for the Cypriot presidency of the European Union, a musical was created by a nationally-recognised musician, performer and producer alongside Cyprus Alzheimer Association. *'DI-MENTIA' A New Musical* highlights the modern day issues related to dementia through a compelling story and emotive music and lyrics. The show opened in early September 2012 and a large-scale advertising campaign took place during September and October. The immediate audience for the show reached 5,000 and the campaign is believed to have extended to around 100,000 individuals.

ASSOCIATION**Egypt Alzheimer's Society****PROJECT TITLE****Advanced dementia care educational programme**

This 18-month project aimed to train highly qualified carers, such as those who take leadership of healthcare teams. The programme included lectures, interactive sessions, case studies and clinical rounds.

ASSOCIATION**Deutsche Alzheimer Gesellschaft (Germany)****PROJECT TITLE****Education in municipalities**

Deutsche Alzheimer Gesellschaft developed this programme to educate those who may come across people with dementia in their working lives, such as policemen, firemen, salespeople and bank employees. People with dementia were consulted during the planning stages of the programme and modules were developed tailored to the profession of those being trained. The programme, which ran from 2007 to 2010, focussed on the basics of dementia and how best to communicate with a person with dementia. Films and manuals were prepared to support the programme.

**ASSOCIATION****Alzheimer Scotland****PROJECT TITLE****The National Dementia Champions Programme**

Funded by the Scottish Government and developed in partnership with the University of the West of Scotland, this programme aims to enhance the knowledge of staff in acute hospital care and encourages participants to become agents for change. The programme consists of five interactive study days delivered to small, intimate teaching groups with video conferencing used for those in more remote locations. People with dementia alongside their families and friends were involved in the development, implementation and evaluation of the programme. Since October 2011, 300 Dementia Champions have been trained in Scotland.

2nd ADI-MetLife Foundation Awards for Best Dementia Care Education Projects

ADI is extremely grateful to MetLife Foundation for supporting the development of these awards this year. Due to the success of the 1st ADI-MetLife Foundation Awards, it has been confirmed that this award programme will run again in 2014. More details will be sent to ADI member associations later this year.

■ Carer's story

Alex's words

Tina Hackel, Switzerland

I am Tina Hackel and live now in my home country, Switzerland.

Living with my late husband Alex in Florida, USA, we have together, and mostly at home, experienced probably 8 years (it has been 6 since Alex was diagnosed at age 72) with his dementia, probably of the Alzheimer's type.

Looking through my reports and postings I've made to my German online support group for care partners, I'm amazed how gracious, humorous, charming and creative Alex was through his journey with Mr Alzheimer inside his head.

So much of my own stress was due (as I know now) to expectations of catastrophic things happening to Alex, to us as a couple ... which actually never happened.

Alex always found ways to let me know: he still loved me and us, he enjoyed TODAY, didn't much worry about the future, and he appreciated his past without whining about the simple fact – that it was the past. Alex seemed to be so much at peace with himself and his life, he easily could be generous, patient, forgiving and kind towards me, while I tried to share with him my Ups and hide my Downs from him.

Alex surely knew and understood much more than I wanted to show and tell, and sometimes he expressed his insights in loving, humorous, amusing ways, and moments like these would always dissipate and end any tensions.



Tina with her husband Alex in February 2008

So when I cleaned the messy bathroom, adjacent to the master bedroom, after I had cleaned Alex and brought him to bed, and it was after midnight, and I was so tired when Alex called me from his bed:

"Tina, I have to tell you something!"

"Yeah ... what's up?" I grumbled.

"Tina, I love you!"

"I love you, too!" I assured him.

"But," Alex added, "for me it's easier to love you!"

In 2004 we had a heavy hurricane season; three storms raged over tiny Lake Wales, Central Florida within a few weeks. I was in constant alarm and alert, had the Weather Channel on most of the time (unless the power was gone), while Alex complained:

"Nothing else to see but yelling folks in hoods?!"

Then he went to sleep to forget how boring this was. And he

woke up a couple of hours later and asked:

"Was there something with a hurricane? When did I secure the windows? Did I store enough food? Is the car fully tanked? And you are here – I'm so glad – thought you're still in Switzerland!"

"Yes, my love, I'm here always for quite some time, and I'll never leave you again. And today I'd cooked a special meal, and you liked it and then had a good Siesta. I had to be here to do this!"

"Yeah, right!" Alex laughed, "A very good meal. I'll go to sleep a little longer. I'm so glad you're here, so glad, so glad! I love the way you care for me!"

"Tina, do you get your Social Security?"

"What Social Security?"

"Well, what you get when you're 65!"

"No, Alex, I'm not 65 yet!"

I'm so glad you're here, so glad, so glad! I love the way you care for me!

"Oh?"

"I'm 55!!!"

"Tina, could you come over here, please?" Alex calls from his Siesta couch.

"Yeah ... what for?"

"Could you take this blanket and put it over my legs?"

"Sure ... but why don't you grab it yourself. I'm in my office online and ..."

"Because I'm your darling, that's why. I so like it when you put this blanket over me."

"And bring me the dog!" Alex adds after I've left the room again – and gives himself my usual answer:

"I don't bring dogs, ha ha!"

I've bought a very large t-shirt for Alex, it has a map of Florida printed on it.

"See?" I told Alex, "Here's where we lived before we moved, and now we live here!"

"Could you paint a red point, where we are now?" he asked, "When I get lost, I'll always have a map with me!" he smirked.

In moments like these I don't feel I'm talking to Alex who has dementia, but to a very alert and very smart spirit "behind" the brain which has dementia.

To read more of Tina's experience visit <http://tinahackel.wordpress.com>

■ How associations help

First steps to freedom for 'What is Your Name'

Berrie Holtzhausen, Dementia Namibia

In Africa there is a struggle against Alzheimer's and other dementias. After the Africa Alzheimer Congress we are not anymore alone in the challenge of superstitious beliefs (witchcraft and casting out of demons), where scientific truths are exchanged for perceptions which were formed because of a lack of knowledge.

20 October 2012

At 7.45am we stopped at Kapika's Onganda near Epupa falls. Kamati, Juanine and Koos first approached Kapika (the head man) who was sitting outside the wall of his village under a tree. Koos asked Kamati to introduce us to this humble but mentally strong headman of the Ovahimba tribe in the Kunene region.

I first shook hands with him and at the same time presented a chair as a gift to him. I tried my best to explain to him that two weeks ago we'd arrived here on this spot, in his village, and saw someone that really needed some help which we hoped we could give.

There was an old man sitting nearby and Kapika first thought that I was referring to him, and then I said:

"I am referring to your sister", and then he asked us some questions: "can I give her a tablet to cure her", "how will we care for her better than he is caring for her". I then pointed to Venoo and Jyiores, who is also a Himba, and told him that we are taking them to Yakandongong to give them training and bring them back after the New Year to help him and his people to care for his sister. Then there were more questions. Most of the time I didn't understand a word that was going on in the negotiations, but his face and eyes told a story of positivity...at some stage he clapped his hands...a sign of thankfulness.

After about two hours, he was satisfied and even offered us a piece of land, located 20km from him and 10 from where Koos live, where there is a borehole and hand pump and enough water, where we can care for people like his sister. He started to talk about the sister and the trouble they've had over the years with her and still have, but then also told us that "the church" sent people here, praying for her and then told him he can unchain her, she is now cured... and then she wandered off and they found her two days later, far off in the



What is Your Name's 20 metre walk to the shady tree was a symbol for me of her first steps to freedom

HOW ASSOCIATIONS HELP CONTINUED

veld, nearly dead. At that moment, I was livid and anger boiled in me towards “the church” (OK, some church leaders) and their stupid and superstitious beliefs.

A lot happened and then he asked us if we want to see his sister. He also explained to us that she is dangerous: she has hit him once and at night time she tried to strangle the goats and took wood from his village outer walls and made fire. We went to her hut and we greeted her and asked her to come out, as she was not chained to the pole, but only between her feet – they only chain her to the pole at night so that she is not able to strangle the goats and burn the wall.

She came out and asked for some ‘pills’ because of stomach pain, and when I saw her and heard her talking I realised that because she has stomach pain, she tried to make a fire and then tried to strangle goats because she must be extremely hungry – I can’t really fathom more than that, but clearly the goats are means of food and fire the means to prepare it. I still believe her stomach pain was hunger pains.

We took her to a shady tree, gave her water to drink and cookies to eat; she was calm, talkative...but clearly confused. She kept on talking about the past as if it was her reality. We’ve asked her what her name is, because we “outsiders” don’t know and Kapita never mentioned her name once. She only said: “My name is... What Is Your Name!”

She can’t walk upright and she is very dirty, extremely neglected physically and emotionally.

12 December 2013

When I came yesterday, I had a meeting with Kapika and his two wives about the process that needed to happen. You see, I needed to literally remove chains from an elderly

lady, she needed to be washed and given fresh and clean clothes.

The purpose of my visit spread like wildfire and before long a family member of the elderly lady stood before me. He says he knows about a man in his 30s that is like his elderly aunt. Not very long after that, there are 10, no 12, people like her. But then I ask him to tell me about his aunt of his that I’d come to help.

I ask him her name and in the sand he writes; NDJINAA. Then he tells me her incredible story. When her mother was pregnant with her, she started bleeding and went to the headman. They decided to give her some traditional medicine to bring out the baby as they saw the bleeding as a bad omen. But before they could give her the medicine, Ndjinaa was born. Her name means; I know your mother, but I do not know you. This, my friend, tells me that she came into this life as threat and not as a gift. There are several more stories about her. About people that were murdered for their belongings and now their souls have returned and live in her.

We cut her chains, removed all the old straps and provided her a nice big bath. (I brought along about 100l of water in plastic drums). The three care workers (also trained by us) gave her a bath and new, clean materials to be used as a dress that I bought yesterday in a tin hut at Epupa for N\$35 (US\$3.50) per meter. Four meters of fabric and two dresses – the most she’s ever had in the last 20 years. She even slept on the ground because the skin she used to sleep on got too dirty and should have been burnt a long time ago.

While the care workers gave her a bath, Koos and I negotiated with Kapika and his men about the ground we needed for the Ovahimba Dementia settlement that we are planning. I also indicated that every family that brings a person with dementia must donate two goats or a cow and must build a hut for

the sick person. With that, our three care workers appear with a brand new grandmother... and she smiles. She even walks upright and takes a longer step with every uncertain step into the future.

I suspect that she had very little drinking water, not to mention the 10 litre water she just bathed in, in the last 20 years. Everybody stands and claps their hands.

I tried to have a conversation with aunt Ndjinaa, but when I called her by name, she said I shouldn’t talk to her; I will only bring bad luck on myself.

I will sleep under my truck tonight to see how the situation with aunt Ndjinaa develops. She will sleep with the care workers in the tent. Here, where I sit, I can hear them talk. Every now and again she also comments on something.

The police and six soldiers have also been here. They are from Okongwati, a town about 30km south of here. The bush telegram has also reached them. I had the opportunity to give them a lesson on dementia. They told me they knew her and that she has been chained for as long as they can remember. I then took them into the tent to show them the new Ndjinaa. The woman among them (called Hello) could not help but smile.

12-12-12 has been one of the most beautiful days in my life. I had the opportunity to see a person freed from chains.

21 May 2013

It was a wonderful event, unchaining her. She has now been cared for by Dementia Namibia for the last five months and care workers from their tribe, trained by Dementia Namibia. From being labelled as a witch, chained for 20 years, never being touched or cared for... to an unchained, free, friendly and loving grandma for the kids of a Himba village.

■ Living with dementia

Two stigmas: one in society and the other within myself

Mr Masahiko Sato, Japan

When my doctor told me that I have the Alzheimer's type of dementia in 2005, my mind went blank and I could not think of any question to ask. Then I read every book I could find on Alzheimer's to learn about it. But the more I learned, the more devastated I became. All the books seemed to be dedicated to detailing a roadmap to despair. I felt as if they were trying to convince me that I can

no longer "think" nor "live a normal life" once I develop dementia, and that I will forget who I am and lose all of my will and emotion in time.

Now I can tell what was written in those books was not true. Human beings cannot be defined by what they can/cannot do. My sense of self will not be deprived by anyone. I can decide how I live and create my way by myself.

Living with dementia, I came to know that there are two stigmas. I found one inside of myself. Caught up by the stigma that says "I would not be able to do anything," I was paralysed by the fear of failing. The other stigma exists in society. It says that "I cannot think anymore" and "I cannot understand anymore". No! I defy! They are NOT TRUE! Society contains a stigma and it generates another stigma inside of me. These stigmas are two-fold, taking away my power of living a life of dementia and obscuring my hope for living with dementia.

Mr Masahiko Sato – a short biography

Graduating from a private university with B.S. in engineering, he taught mathematics at an elementary school for a short time, and moved to Tokyo to work as a system engineer at a computer retail company. After suffering from bad headaches for some years, he was undesirably transferred to other sections due to "his incompetent work performance." Eventually he was diagnosed with early onset Alzheimer's disease in 2005, at the age of 51. He took medical sick leave on the very next day after his diagnosis, partially because of a worsening

relationship with his colleagues, and left the company the following year.

He became a Christian in 1994 in the midst of an unknown decline of health, searching for his meaning of life. Through the church charity activities, he became a foster father to children in Thailand, the Philippines and Bangladesh, to whom he travelled by himself to meet in person.

Now he volunteers, teaching mathematics to the local children, and is engaged in activities of and by the people living with dementia coming out to speak up to the

society. He lives alone with the assistance of helpers.

These days, he enjoys going to church, singing in a choir and glorifying God. Yet he feels his symptoms are progressing. His ears are over-sensitive to noises, his body gets tired easily, lacking in motivation for doing anything at times. The buzzing in his ears is getting worse, and he is experiencing a decline in concentration, penetration, and attention.



The Brain Dialogues
cheba.unsw.edu.au/blog

CHeBA
Healthy Brains Positive Ageing



IMAGINE A WORLD WITHOUT DEMENTIA...

This may seem to be a distant dream, but steps toward this ultimate goal are being taken by the Centre for Healthy Brain Ageing (CHeBA) which is co-directed by Professor Perminder Sachdev & Professor Henry Brodaty.

Follow CHeBA's blog, The Brain Dialogues, to read about the latest developments in the field of brain ageing, Alzheimer's & other dementias.

■ Research update

Dementia and your teeth

Dr Peter Foltyn, Conjoint Senior Lecturer, UNSW & Dental Department St Vincent's Hospital and Consultant Dentist Sir Moses Montefiore Nursing Home, Australia and Jayne Braunsteiner, Dental Hygienist, Sir Moses Montefiore Nursing Home, Australia

Good dental care is generally considered to be a shared responsibility between the individual and their dental provider together with the maintenance of a healthy diet. However, as dementia progresses, the ability of the individual to look after their teeth decreases. Lack of oral care can lead to accelerated tooth decay and dental abscess formation as well as gum infections which can then impact on general health and quality of life. Oral pain and discomfort can be devastating, compounding psychosocial problems, disrupting family dynamics and frustrating nursing home staff and carers. As appearance, function and comfort suffers so may an older person's self-esteem, dignity and confidence. Residents with dementia in nursing homes may find that oral health deteriorates quite rapidly, primarily due to a lack of access to dental care.

Poor oral health – a global problem

The World Health Organisation (WHO) has expressed concern that the oral health of older people is widely neglected. Based on a global survey of older people WHO has called for public health action by strengthening health promotion, integrating disease prevention and improving age-friendly primary oral health care. Exclusion



Cancer of the gum and inside of the lip which would have been diagnosed sooner had the patient seen their dentist regularly

of cognitively impaired older adults in the past has led to wide spread under reporting of poor oral health status. Mouth cancers generally occur in older age and as there is no diagnostic screening available regular dental visits may also pick up early mouth cancers which could be treated conservatively.

Link between gum disease and Alzheimer's

Antibody levels to the bacteria involved with gum disease have been demonstrated to be higher in those with Alzheimer's and as inflammation associated with gum disease has been found in the brain it may be a potential trigger for the disease. As the costs associated with maintaining a clean and healthy mouth are miniscule compared to the costs associated in managing Alzheimer's, oral and dental care must be part of every older person's care plan. A clean and healthy mouth is a priority for the elderly.

Ways to help

The amount of assistance a carer or relative needs to provide depends on the stage of dementia.

- *Early or mild stage* – the individual may require no assistance.
- *Mid stage* – the individual may require some degree of reminding or supervision.
- *Late stage* – the individual will require supervised oral care.

How to improve access to the mouth

People with mid to late stage dementia often exhibit neurological reflexes or involuntary responses that can be a problem when attempts are made to access the mouth, teeth or dentures such as closing their lips, clenching

their mouth, biting or moving their head.

The most useful strategy to improve communication with cognitively impaired adults is to break the task down into small achievable steps.

What not to do

When cognitive impairment is present the individual will need guidance in maintaining good oral and dental habits.

- Don't forget to clean the back teeth if you are providing the dental care.
- Don't clean the tongue with a hard tooth brush as this may hurt.
- Don't give lollipops, chocolates or cake when visiting.
- Don't offer juice, cordial or soft drinks. Diet or sugar free drinks can be quite acidic and if there is a dry mouth present decay can be very rapid.
- Don't smoke.
- Don't mix medicines with jam.

As dementia, in the majority of cases, occurs later in life and life expectancy is increasing globally the number of older people living in the community or in residential care will inevitably increase significantly. When health declines or when an individual is no longer able to properly care for him- or herself the benefits of a lifetime of good dental care can often become undone rapidly when neglected. Families and carers must be aware that there may be pain and discomfort associated with poor oral and dental health which the individual may not be able to verbalise. They should be proactive in arranging dental care which should be aimed at preserving function and comfort.

This information was taken from the new ADI factsheet, Dementia and your teeth. Visit www.alz.co.uk/ADI-publications to see the full text with references.

■ Conference news

International Memory Walk

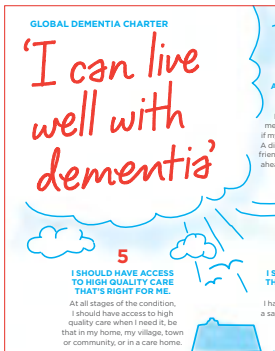


A particular highlight of the conference was an International Memory Walk hosted by TADA Chinese Taipei, which took place around Taipei City Hall. More than 3000

participants joined the walk, including President Ma Ying-jeou who announced the government's commitment to improving the lives of people with dementia and their carers.

The Chinese calligraphy on the International Memory Walk t-shirts was written by Mr Tang who attends TADA Chinese Taipei's Family of Wisdom. The words act as a reminder to people to exercise their body and mind, and to interact with people in order to reduce the risk of dementia and maintain a healthy brain. The characters also call for people and government to take action for memory and dementia.

ADI and Bupa launch dementia charter



Together with international healthcare company Bupa, ADI launched a joint Global Dementia Charter, *I can live well with dementia* on 18 April. The Charter outlines the rights that people living with dementia around the world should be able to expect to allow them to live well.

Bupa and ADI are using the Charter to call on governments to develop national dementia plans and ensure the 10 point Charter becomes a reality.

The Charter has been written from the perspective of someone living with dementia and can be used as a benchmark against which national dementia care and support can be judged. It outlines what should happen at each stage of the dementia journey, from an individual having the right to a diagnosis in order to help them plan for the years ahead when their needs will change, right through to families having adequate support when a loved one passes away.

The Charter is supported by 'enablers', a list of actions and accountabilities that outlines what families, friends, carers, healthcare professionals, commissioners or purchasers of care, healthcare providers, society and governments can do to improve dementia care and support in their country, alongside the development of a national plan.

Joint promotion of the Charter has occurred in countries with both an ADI member association and a national Bupa office, including Australia and Spain. Thanks go to those who continue to support the Charter.

To read the Charter visit www.alz.co.uk/global-dementia-charter

New focus on dementia and nutrition



In partnership with Compass Group, a world leading food and support services company, ADI has prepared a joint summary report on dementia and nutrition ahead of a full report to be released later in the year.

The summary document introduces a number of areas of research on the relevance of nutritional factors to primary and secondary prevention of dementia, undernutrition in dementia and interventions to improve the nutrition of people with dementia.

The forthcoming report, produced by the new 10/66 Observatory, will contain a full and more detailed review of the available research in these areas with additional input from international experts in the field.

To view the summary report visit www.alz.co.uk/nutrition-report

2013 ADI Award winners

During the conference, ADI recognised the great efforts made by Chinese Central Television (CCTV) and The Hon Mark Butler, Australian Minister for Mental Health and Ageing, in improving the lives of people with dementia and their carers.

The ADI Award was presented to CCTV during the conference Opening Ceremony. This recognition followed CCTV's recent contribution to raising awareness of dementia through news coverage in China.

The award for The Hon Mark Butler came after many years of support for the cause from the Australian Minister. His work in Australia has positioned the country at the forefront of the dementia cause, influencing governments around the world to develop similar support and service systems. His award was presented in April by Alzheimer's Australia President Ita Buttrose at an event in Sydney.

To find out more about the ADI Award visit www.alz.co.uk/adi-award

Collaboration expands dementia services worldwide

Lori La Bey, founder of Alzheimer's Speaks, has been on a thirty year journey with dementia via her mother. She is a keynote speaker and trainer on dementia, care culture and social media. Lori engages audiences through Emotional Based Training™ techniques. She gets people to shift their mind-sets by feeling the need to do so on a heart and soul level.

ADI has joined forces to raise global awareness with Alzheimer's Speaks, an advocacy based company that leverages social media to raise awareness of dementia, and educates families, businesses and communities. 'Given that ADI is the association for all Alzheimer associations worldwide and that Alzheimer's Speaks has been named the #1 influencer online for Alzheimer's by Sharecare and Dr Oz, it only made sense to work together,' said Lori La Bey, founder of Alzheimer's Speaks. The partnership plans to increase awareness and education of Alzheimer's disease and other forms of dementia along with building a sense of community to help remove the fear and isolation the disease causes.

'By working collaboratively each organisation can do what they do best'

Marc Wortmann, Executive director of ADI, said, 'One of ADI's main objectives is raising awareness. By working with Alzheimer's Speaks we feel we can do this in a very effective way that has no boundaries through the use of the internet. We can reach people all over the world.'

ADI members are encouraged to participate in a variety of platforms Alzheimer's Speaks offers. Not only can members expand their knowledge base of best practices, but they could be a potential guest on one of the platforms listed below, sharing what their organisation is doing.

Alzheimer's Speaks is known for providing safe environments which are educational and supportive;



raising the voice of all to share services, products and tools. They empower people to be collaborative and have honest conversations to help remove the stigmas attached to Alzheimer's disease and others dementias. By connecting people through non-threatening platforms they build a better dementia tool box for all.

Below are highlights of some of Alzheimer's Speaks platforms which are available to ADI members, their families and clients free of charge. They can even link back to these platforms from their own websites.

Alzheimer's Speaks Radio is the first programme dedicated to shifting our dementia care culture. The show airs live four times a month. Alzheimer's Speaks encourages listeners to be part of the conversation by calling in or using the chat box to pose a question or comment. All shows are archived so you can listen at your convenience. Airing days and times vary to accommodate a variety of time zones. If you think your organisation would be a great guest on the show please use the contact details below.

Dementia Chats™ is a free webinar series where the experts are those diagnosed and living with dementia. Families and organisations are using these sessions for educational purposes, training and support groups. Typically, sessions are on the 2nd and 4th Tuesday of each month starting at 3pm EST, 2pm

CST, 12pm PST, 8pm London.

The webinars are easy to access and participants can use the chat box to make comments or pose a question. All sessions are recorded and archived for viewing later.

Alzheimer's Speaks Blog has won several awards for its content, much of which is related to personal experiences and best practices of how to live with the disease, not as it. If you are interested in submitting an article to raise awareness for what you are doing or believe regarding dementia care, email Lori at the address below.

Due to the growing popularity of the Memory Cafés and Alzheimer's Cafés around the world, we would love to have each one listed in the Alzheimer's Speaks Collaborative Resource Directory. If you have a Memory Café or Alzheimer's Café please contact Alzheimer's Speaks to get directions as to how you can add yours. It is a quick and easy process that will take you five minutes to input.

There are also a variety of free tools for you to use on Alzheimer's Speaks.

You can utilise the International Collaborative Resource Directory for Dementia to let people know of your organisation, services, products or tools. You can also add additional services, products or tools that you believe are valuable. Alzheimer's Speaks will waive the fee for ADI members. For directions on how you can add your caring support services, blogs, books, newsletters, videos and more to the directory contact Lori at the address below.

If you are looking for a positive and inspirational speaker or would like to find out more about the tools and services mentioned above email Lori@AlzheimersSpeaks.com or visit AlzheimersSpeaks.com

■ News

The World Health Assembly 2013

ADI Executive Director Marc Wortmann and Policy Adviser Mike Splaine attended the World Health Assembly in Geneva, Switzerland in May alongside representatives from the 193 World Health Organization member states.

The main topic on the agenda this year was the Global Action Plan for non-communicable diseases 2013-2020. Over the past three years ADI has worked hard to call for the inclusion of dementia in the non-communicable disease (NCD) plan and, although it was not decided that this should be added, there is clearly greater recognition that the risk factors for the four major NCDs (cardiovascular disease, diabetes, cancer, and chronic respiratory disease) are shared with a number of other conditions including Alzheimer's disease.

In an appendix to the resolution it states that:

'A comprehensive response for prevention and control of noncommunicable diseases should take cognizance of a number of other conditions. Examples of these include cognitive impairment and other noncommunicable diseases, including [...] Alzheimer's and Parkinson's diseases [...]. The presence of these conditions may also influence the development, progression and response to treatment of major noncommunicable diseases and should be addressed through integrated approaches.'

During the event the Assembly also adopted the Mental Health Action Plan 2013-2020, which features references to dementia. There was also a great deal of focus during the Assembly on the UK's new initiative to add dementia to the G8 meeting in June and summit in September (see front page).

ADI and Rotarians allies in Caribbean Dementia Awareness

Over 500 Rotarians of Rotary International District 7020 attended their 39th District Convention from May 15-18, 2013 in Tortola, British Virgin Islands.

Based upon a commitment made last year upon signing of the Caribbean Dementia Awareness Advocacy Alliance, District Governor Vance Lewis sent an invitation to ADI chairman Jacob Roy to address the district convention on Alzheimer's disease and dementia. ADI representative for the WHO/Pan American Health Organization and Secretary of the Sint Maarten Alzheimer Foundation, Raymond Jessurun attended the event, giving a presentation and sharing information from an exhibition stand.



Raymond Jessurun represented ADI

Recognition for James McKillop



James with delegates from Nicaragua at ADI's Alzheimer University in 2010

ADI was delighted to learn that James McKillop, who is living with dementia and has attended a number of ADI events in the past, has been awarded an Honorary Doctorate from the University of Strathclyde in Scotland for his work in the dementia field. James will receive his award at a ceremony in November and ADI wishes to congratulate him on this achievement.

10/66 Lancet success

ADI would like to congratulate the 10/66 Dementia Research Group on achieving 8th place in *The Lancet's* Top 10 Psychiatry articles of 2012/13.

The 10/66 article, published in May 2012, was titled *Dementia incidence and mortality in middle-income countries, and associations with indicators of cognitive reserve: a 10/66 Dementia Research Group population-based cohort study*. The study results showed supportive evidence that in middle-income countries, as in high-income countries, education, literacy, verbal fluency and motor sequencing can substantially protect against the onset of dementia.

The Top 10 Psychiatry articles, chosen by *The Lancet*, are selected to reflect the diversity of psychiatry topics that they publish.

■ News



1st Patient Solidarity Day

On 30 October patient advocates across Africa will mark the first Patient Solidarity Day, an initiative developed in Kenya and Uganda and being coordinated throughout the African region by the International Alliance of Patients' Organizations (IAPO).

The focus of the day will be on improving lives through patient-centred healthcare across a number of disease areas.

Events will take place in Cameroon, Ghana, Kenya, Liberia, Malawi, Nigeria, South Africa, Uganda, Zambia and Zimbabwe.

ADI is supporting IAPO's call for ADI members in the region to participate in Patient Solidarity Day activities by partnering with IAPO members or holding their own event. A toolkit and support will be available from IAPO in preparation for the day.

For more information visit www.patientsolidarityday.org

High altitude fundraising supports Friends of ADI



Bob Kerr on Mount Everest

In the March issue of *Global Perspective* readers were informed that Bob Kerr from Scotland was raising funds for Friends of ADI during his attempt to reach the summit of Mount Everest, the Earth's highest mountain.

Unfortunately, Bob did not reach the summit as he experienced loss of vision in one eye when he reached the camp at 7,850m (25,750ft). However, Bob did safely return back down the mountain and, during his expedition, raised almost £1,300 for Friends of ADI, one of three charities he had chosen to support in his attempt.

ADI would like to thank Bob and all of those who donated to Friends of ADI for their support

and contributions. Congratulations also go to Bob on reaching a new high-altitude personal best and returning home safely.

To read Bob's daily blog posts during his expedition visit www.bob-kerr.com

In the next issue of *Global Perspective*

- Alzheimer University for emerging associations
- Young Caregiver Platform
- World Alzheimer's Month 2013

September World Alzheimer's Month

Dementia: a journey of caring

www.alz.co.uk/WAM

