



Alzheimer's Disease
International

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Global Perspective

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

Be a part of the World Alzheimer Report 2012

This September, ADI will launch the World Alzheimer Report 2012. This year's report will focus on the stigma surrounding dementia worldwide.

To assist us in the development of this report, we are looking for people with dementia and carers who can offer a small amount of time to answer some questions relating to their thoughts on stigma through an online survey.

To find out how you can get involved email info@alz.co.uk and more details will be sent to you.

The World Alzheimer Report is gaining an international reputation for providing the most up-to-date information on dementia worldwide



Changes to your *Global Perspective*

See the new *My perspective* section containing contributions from carers and people with dementia, and our new feature highlighting how national Alzheimer associations help.

We have also introduced the new *Member profile*, where each issue of the newsletter will dedicate a page to the great work being carried out by one of ADI's member associations.

The new *My perspective* section





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 20 April 2012.

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Editorial



Daisy Acosta, Chairman

The beginning of March marks the end of my tenure as Chairman of Alzheimer's Disease International. The past three years have been a whirlwind of new experiences, new challenges and new developments.

I would like to wholeheartedly thank all within the dementia movement who have contributed to the work of ADI and have supported me in my role over the past three years. Your involvement has been key to our success.

I would like to give special thanks to people with dementia and their families across the world, as serving them as Chairman of ADI had enriched my knowledge of their struggles and their needs. This has made me not only a better person, but also a better professional working in the dementia field.

I now hand over chairmanship to Dr Jacob Roy, the founder of the Alzheimer's and Related Disorders Society of India (ARDSI) and a true supporter of ADI. I am confident that he will be a strong and valuable leader and I wish him all the best in guiding ADI through the very successful times to come.

I look forward to seeing many of you at our international conference this month and, to those who are not able to join us, I wish you all a very prosperous future with long-lasting involvement in the global dementia community. I may be leaving this position, but my fight against dementia will not end here and will continue for as long as dementia exists.

Events

7 – 10 March 2012
27th Annual International Conference of Alzheimer's Disease International
London, UK
Email: adi2012@mci-group.com
Web: www.adi2012.org

8 – 11 March 2012
6th World Congress on Controversies in Neurology (CONy)
Vienna, Austria
Web: www.comtecmed.com/cony/2012

9 – 12 May 2012
12th International Stockholm/Springfield Symposium on Advances in Alzheimer's Therapy
Stockholm, Sweden
Email: ahamilton@siumed.edu
Web: www.siumed.edu/cme/alzheimer

28 May – 1 June 2012
IFA 11th Global Conference on Ageing
Prague, Czech Republic
Email: puldova@guarant.cz
Web: www.ifa2012.com

14 – 19 July 2012
Alzheimer's Association International Conference 2012 (AAIC)
Vancouver, Canada
Email: aaic@alz.org
Web: www.alz.org/aaic

4 – 6 October 2012
22nd Alzheimer Europe Conference
Vienna, Austria
Email: www.alzheimer-europe.com/EN/Conferences

18-20 October 2012
VI Congreso Iberoamericana de Alzheimer
Santiago, Chile
Web: www.alzheimeriberoamerica.org

26 – 28 October 2012
15th Asia-Pacific regional meeting of ADI
Beijing, PR China

Members' forum

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

BULGARIA

Twinning Programme success

Compassion Alzheimer Bulgaria have been chosen to receive an award for their involvement in ADI's Twinning Programme by a collective of European Foundations.

The *Living well with Dementia in the Community Awards* were launched in March 2011 by the European Foundations' Initiative on Dementia, made up of The Atlantic Philanthropies, Fondation Médéric Alzheimer, the King Baudouin Foundation and the Robert Bosch Stiftung.

The objective of the award is to encourage the development of projects to support a good quality of life for people with dementia and their families, whilst providing them with the opportunity to take part in activities within the local community.

The award was presented to Compassion Alzheimer Bulgaria for working together with others outside of their country to develop and implement an effective awareness-raising programme aimed at reducing stigma and promoting inclusion within the general public.

Over eighty applications were submitted for the award, which offers prizes of up to EUR10,000 for the ten winning projects. Representatives from Compassion Alzheimer Bulgaria attended the award event in Brussels, Belgium on 16 January to receive their prize.

ADI would like to congratulate Compassion Alzheimer Bulgaria on their award and thank them for being a part of the Twinning Programme.

For more information about the work of Compassion Alzheimer Bulgaria contact compassion.alz@abv.bg

CROATIA

Volunteer recognition



Mira Dajčić (left) receives her award alongside Alzheimer Croatia President, Ninoslav Mimica (right)

Alzheimer Croatia was delighted to learn that their vice-president, Mira Dajčić, had been named Volunteer of the Year 2011 during the European Day of Volunteers in December.

The Ministry of Family, Veterans and Intergenerational Solidarity and the Delegation of the European Union presented the award, which is the highest granted to volunteers in Croatia.

Mira has played a vital role in improving the quality of life of people with dementia and their carers in Croatia through her work with the association. As well as conducting regular meetings with family members, running self-help groups and showing great commitment to the association's helpline, Mira has also written a number of professional papers and information materials.

ADI would like to congratulate Mira on receiving such esteemed recognition.

For more information about the work of Alzheimer Croatia visit www.alzheimer.hr

GERMANY

Forum for people with dementia

In response to increasing demand for information through their helpline, Deutsche Alzheimer Gesellschaft (DAIzG) are making it easier for people with dementia to access the resources and platform that they need. A new section, *Menschen mit Demenz* (People with Dementia), specifically for people with dementia is now available on the DAIzG website.

The page offers information about a range of lectures, articles and books and the support services offered by DAIzG, including the Alzheimer-Telefon (helpline) and a host of information booklets. The page also features a link for people with dementia to download a help card, which can be used in an emergency situation.

The page also lists the contact details of existing support groups for people with dementia and highlights the involvement of people with dementia in national events.

For more information visit www.deutsche-alzheimer.de

USA

Dementia funding secured

On 23 December, the Alzheimer's Association received news that their advocacy efforts had paid off, with funding being secured by the country's government for Alzheimer's research and programmes to support people with dementia and their carers through the National Alzheimer's Project Act (NAPA).

The NAPA Advisory Council on Alzheimer's Research, Care and Services, which will receive \$250,000 in funding, is overseeing the development of the country's first national Alzheimer plan.

Congress will also fund the National Alzheimer's Call Center, a 24-hour, seven days a week helpline run by the Alzheimer's Association as a public-private collaboration with the federal government.

An additional \$12 million is directed to the Department of Defence Peer-reviewed Alzheimer's Research Program, which was established in 2011. This programme focuses on innovative and outcome-oriented research that is relevant to military personnel and the Alzheimer's community. The National Institutes of Health also received an increase in their research budget. A new programme within the National Center for Advancing Translational Sciences, entitled the Cures Acceleration Network, has also been created as a result of new funding.

Funding for the Healthy Brain Initiative at the Centers for Disease Control will also be maintained this year. This initiative is another example of a successful public-private partnership between the Alzheimer's Association and the federal government.

For more information about the advocacy efforts of the Alzheimer's Association visit www.alz.org

ASIA PACIFIC

Regional meeting a great success

Delegates from across the Asia Pacific region gathered in Bangkok, Thailand from 11 to 13 January for the 14th Asia Pacific Regional Meeting of ADI. The conference, hosted by ARDA-Thailand, featured a strong programme and lively exhibition area with great representation from ADI member associations across the region.

Some high-quality speakers addressed delegates during the conference plenary sessions. Of particular note was a talk on dentistry and oral health for people

Dementia newsflash

■ Caribbean

Fundacion Alzheimer Aruba recently played host to other associations within the Caribbean region to further discuss the formation of a regional group to strengthen ADI members within the Caribbean.

■ Iran

Iran Alzheimer Association have signed Letters of Understanding with four universities who will send students to the Association's centre for training.

■ Italy

Federazione Alzheimer Italia has launched a fundraising campaign to support their *Pronto Alzheimer* helpline facility. The campaign encourages members of the public to send an SMS message to any number covered by one of seven mobile phone networks to donate two euros.

■ Singapore

ADA Singapore have created a Facebook App, *Sort Me Out*, which simulates the memory loss experienced by a person with dementia by slowing erasing the contents of an individual's Facebook account.

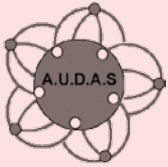
with dementia, which offered useful information on a lesser-known topic.

ADI would like to congratulate all at ARDA-Thailand for ensuring the conference was a great success and a very memorable event.

For more information about ARDA-Thailand visit www.azthai.org

Member profile

In a new feature we look in detail at the work of one of our 76 members worldwide



URUGUAY

Asociación Uruguaya de Alzheimer y Similares – AUDAS

Day centre for people with dementia

For 20 years Asociación Uruguaya de Alzheimer y Similares (AUDAS) has worked continuously to serve people with dementia, their families and carers, and society in general. In addition to raising awareness and educating the public to reduce the stigma associated with the disease, they also host professional conferences, training courses, seminars and other activities at the national level. In addition, they run self-help groups in Montevideo and the interior branches.

Inspired by international experience of dementia-specialised day care centres, such as those in Spain, Canada, the USA and the UK, AUDAS have developed their own centre. With the objective of improving the treatment of people with dementia from a psychosocial perspective, the centre will be open five days a week to those in the early stages of the disease.

The centre aims to provide a specialised care service as a way of reducing stress for the person with dementia and the primary carer and to lower the direct and indirect costs associated with the disease. The centre's staff will be qualified to provide professional advice and training for family carers as well as for college student interns as a means of improving the quality of care and training future professionals. AUDAS also intend to use the experiences gathered at the centre to develop their public outreach efforts.

The centre will host a variety of activities as arranged by a Task Force Coordination team who will

be responsible for the technical implementation of the centre's proposal. These include:

- Reception, assessment and monitoring: All people with dementia using the centre will initially undergo a medical evaluation to determine their needs and ensure they are placed on an appropriate intervention programme. The technical team will then monitor their progress.
- Cognitive stimulation programme development and creative processes: This programme consists of two dimensions: rehabilitation and maintenance. Rehabilitation will include: a) interventions with a small target group using psychological techniques, b) working to stimulate creative and manual skills from the application of an occupational therapy programme. Maintenance activities will include orientation to reality and presence in everyday life, such as reading newspapers and remembering names, dates and birthday celebrations.
- Psychosocial intervention programme functions: This programme consists of three dimensions: a) psychotherapeutic groups and psycho education emotional support for families and carers of people with dementia, b) timely and individualised counselling where necessary, both for people with dementia and carers, and c) family psychotherapeutic interventions in a timely manner according to the needs of each case.

- Intervention programme on physical capacity: This programme involves physical activities with specific exercises designed to enhance movement and body image. This will be adapted according to the needs of each person. All people with dementia attending the centre will be involved in physical activity unless they have a specific disability that prevents them from doing so. This programme will be integrated into others ranging from functional activities, such as lunch and snacks, to conducting guided tours and listening to shared music.

The Task Force will continuously monitor the development of different programmes as well as each individual person with dementia and carer's progress through a multi-level evaluation.

The centre's workforce will consist of a medical geriatrician, a psychologist, a social assistant, a professor of physical education, a music therapist, a nursing assistant, and eventually an occupational therapist. University students will support the team through apprenticeships.

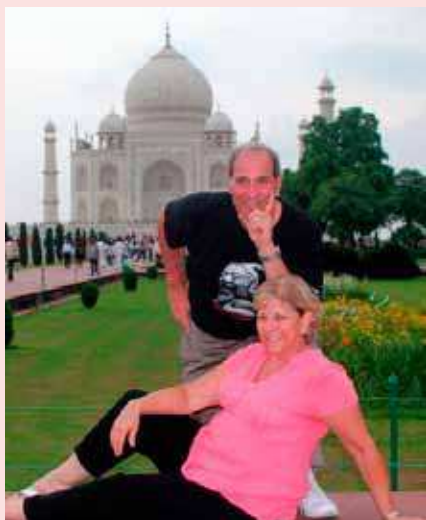
A range of resources will be available at the centre, including ergonomic chairs, tables, appropriate equipment for physical exercise, mats, balls, hoops, games, puzzles, craft materials, painting equipment and books as well as a television, DVD player, camcorder, camera, music player and speakers.

For more information about AUDAS and their work visit audas.wordpress.com

■ Living with dementia

A person-centered experience

Don Bandler, USA



Don with his wife, Jane

Thank you for the opportunity to share my experience of living with Alzheimer's. I am Don Bandler. I am 64 years old. I was diagnosed with Alzheimer's disease in 2008. I first noticed memory problems in 2005.

Let me take a moment to tell you a little about myself, so you will have an idea of what this disease has taken from me. Then, multiply my difficulties by the millions of people living with Alzheimer's, and you will have an idea of its costs to our society.

I had a 27-year career in the Foreign Service. I served in West Africa, France, Germany and as Ambassador to Cyprus. I was President Clinton's Senior Director of European Affairs in the National Security Council, and later worked as Senior Vice President at Monsanto and then at Kissinger McLarty Associates. I also served as former UK Prime Minister, Tony Blair's Chief of Mission at the Office of the Quartet Representative in Jerusalem. I had the opportunity to work with some of the USA's greatest political minds.

I have a BA with honors from Kenyon College; a Masters degree from St. John's College; and a law degree

from George Washington University. I exercise regularly and eat a healthy diet. Nonetheless, I have early onset Alzheimer's.

Getting a diagnosis is the very difficult first step on this long journey of living with the disease. Back in 2005 I complained to my internist that I was having trouble remembering things. But, not until 2008 did I really start seeing doctors at both Johns Hopkins and the Georgetown University Memory Disorders Clinic. After blood tests, MRIs, PET scans, and a complete battery of psychological cognitive tests, the results were in. The doctors were shocked, but all in agreement. I had early onset Alzheimer's disease. That was in November 2008. It was devastating and overwhelming news for me and my family. I still had many career and personal dreams on my agenda and tangled brain neurons were not part of those dreams.

When first diagnosed, I was determined that Alzheimer's would not change my life ... but it has changed my life and the lives of my wife and children. Alzheimer's is not just an individual disease, it is a family disease. I am so lucky that I have my wife, Jane, who supports me and encourages me to pursue those things that interest me. We work hard to keep the lines of communication open, both within our family and amongst our friends. We take each day as it comes. I am determined to continue being involved in as many activities as I can, despite the hopelessness of the diagnosis.

I still enjoy going to think tanks, attending lectures and conferences about international affairs. Nonetheless, these are now more difficult for me to follow than in the past. I've noticed that organising and keeping my daily schedule has also become difficult. I feel the disease slowly taking things from

me. I try to stay focused on the things that I have, and not the things that I have lost. I am continuing to do the things I love to the best of my ability.

According to the Alzheimer's Association, there are 5.4 million Americans who have Alzheimer's. Every 69 seconds, someone in America develops Alzheimer's. By 2050 the number of people with Alzheimer's will approach 11 to 16 million. There is no known cure for Alzheimer's. There is no effective treatment for Alzheimer's.

As a person living with Alzheimer's it is important to me that I have a support network from my family and friends. I could not navigate this disease without that help. It is important to me to live my life and try to do everything I can and want to do now, as I am aware it is a progressive disease. It is important to me that we find a cure and develop medicines that work, and find the money for the research needed so we can reach these goals. In the meantime, it is also important to me that a national plan be put into place to improve diagnostic testing and to provide a clear road map for the patient and his/her family after receiving a diagnosis of Alzheimer's, explaining where to go for the help and support we need.

Alzheimer's is the sixth leading cause of death in this country. But even more significant is the horrifying fact that among the top ten causes of death, Alzheimer's is the only one that cannot be prevented, cured or even slowed. While death rates have declined for most major diseases, deaths from Alzheimer's have risen 66% during this same period.

I do not want my children and grandchildren to know this disease. My mother-in-law died from Alzheimer's 13 years ago. She had the same wish – that her children would not know Alzheimer's. It is high time we find a cure.

Thank you!

■ Carer's story

What is normal?

Frances H Kakugawa, USA



Frances H Kakugawa

Normal is like beauty, all in the eyes of the beholder.

When I was a caregiver for my mother who had Alzheimer's disease, I saw two normal worlds between us, hers and mine. Once I acknowledged that her world was as normal to her as mine was to me, I stopped using reason and logic to bring her into my world. I embraced the new person who was evolving right before my eyes and stopped denying the person that she was.

When my mother saw a "black thing" coming out of a painting on her bedroom wall, I said, "I'll take it away so you won't see the black thing." I dignified her world by not denying what she saw. I believe there is a window to her mind that opens now and then, and allows her to know that the world in which she now lives has become strange and scary. To remind her of this can be cruel and dehumanising.

Caregiver Elaine shows how she entered her mother's world when her mother saw a man and a girl in bed with her. This is an excerpt from one of her poems that appears

in my book *Breaking the Silence: A Caregiver's Voice*.

Humph, I say.

"...She shouted about that girl and that man in bed with her."

"Where's the man?" I stammer.

"Next to me, Can't you see?"

"And where is the girl?"

"Can't you see? Against the wall!"

"Well," I say, "Let the man sleep against the wall. And put the girl next to you."

"Oh, okay," she utters.

"Back to bed..."

Mary learned to enter her aunt's world.

"My aunt has an imaginary lover. We got into many confrontations when I told her, "What lover? I don't see anyone here." She'd shout back, "Can't you see? He's right here?" And we'd go back and forth like a pendulum, creating such frustration in both of us. Once I accepted her world and told her "Wow, Auntie, he's pretty good looking, huh?" past animosities ended. He's usually there when I visit her now.

People with dementia often turn to babbling in later stages of the disease. Have we thought that maybe we are the ones with language deficiency? Perhaps if we learn to see through their eyes and hear through their ears, we will learn

more of their world instead of being stuck in our own. This may lead us to find a way to give care with less conflict. Once we believe both worlds are "normal", once we open the doors to both our worlds, we eliminate the tug-of-war that often erupts between two parties. By doing so, we dignify the new person who is evolving and by so doing, we dignify ourselves.

A loved one says, "John came to see me today." In your world, John has been dead for over ten years. Enter her world and a comment similar to; "Did you have a good visit?" will bring peace and dignity to that moment. To argue and tell her, "John is dead, Mom. You must have had a dream," drops a jagged rock in the middle of that stream that was flowing so smoothly until you arrived.

But what of our world? Are our loved ones incapable of entering our world? At certain stages of the disease, they won't be able to, not with logic and reason, but there is a place in our world that offers them a front row seat: dining in restaurants or around family gatherings, feeling the wind on their faces, hearing happy voices of family, feeling love and affection through human touch, being connected through conversations, even if they eventually are reduced to monologues. Our world offers the humanity of knowing what it means to be human.

Both worlds need not clash.

Frances H Kakugawa is the author of three books on caregiving and Alzheimers: *Mosaic Moon: Caregiving Through Poetry*, *Breaking the Silence: A Caregiver's Voice* and *Wordsworth Dances the Waltz* (an award-winning illustrated children's book on accepting grandma who's losing her memory). To find out more visit www.francesk.org

■ How associations help

Lower your risk – forget about dementia

In this new feature for *Global Perspective*, we find out how our member associations across the world are helping individuals by providing awareness-raising and support services.

Kathleen D Tresemer, USA

Kathleen D Tresemer is both a journalist and an award-winning fiction writer. She lives with her husband on a small ranch in rural Shirland, Illinois, USA.

I heard something the other day that scared me.

I don't like to admit being scared, and with the exception of big ugly snakes, I don't think I scare that easily. So, when I was asked, "What does Alzheimer's disease look like?" I could visualise a whole lot of things: an elderly patient in a wheelchair; an old guy wandering the streets in his robe; a grey-haired lady in a car, confused and lost. Not pretty images, but not especially scary.

Then, I heard the answer: Alzheimer's disease looks just like me.

I could suddenly imagine myself as that poor patient huddled in a wheelchair, wandering the streets in my robe, or sitting in my car, confused and lost. That was the scary part – I could see myself as a person with Alzheimer's.

Sue Sklar is the manager of Consumer Education and Outreach from our local Alzheimer's Association office. She held a class at Rock Valley College's Center for Learning in Retirement (CLR) called *The Basics: Memory Loss, Dementia and Alzheimer's Disease*. Sue has a down-to-earth, compassionate approach to the topic – in her second half of life, she is a caregiver for her Mom, an Alzheimer's patient.

'It helps to remember that your loved one has a disease of the brain,' she told us. 'They aren't acting that

way to be difficult or make your life miserable.'

I, on the other hand, need no reason to be difficult – I believe we all deserve a few "get out of jail free" cards when it comes to being cranky.

Sue's goal was to teach us the difference between normal age-related stuff and problems that should be addressed by a doctor. The early diagnosis of a brain disorder means initiating early-stage treatments, designed to slow down progress of the disease—that's a good thing!

A friend, Larry, struggled with dementia related to his heart problems and diabetes. He functioned pretty well for several years, with the combined efforts of some new medication and his wonderful wife/caregiver. The medication slowed the progression of his disease for a long time, and aside from the occasional look that said, 'Wait...I'm struggling to remember something,' Larry and his loved ones had quite a few good years after his diagnosis. I recall wonderful times laughing, joking and telling stories – what a gift!

Another pal told me she has an extensive family history of Alzheimer's disease. She said: 'Being a caregiver seems frightening and overwhelming to people who have never experienced it, but it isn't scary if you have a good support system. Exhausting at times, but not scary!'

That class brought up a whole new issue about dementia that never occurred to me, thanks to Dr Ron Petersen, the director of the Mayo Alzheimer's Disease Research Center. In a short video clip, he explained dementia is an age-related disease and, seeing as how the population is

aging, this alone could bankrupt the health care system.

'Baby Boomers will be flooding the health care system over the next couple of decades,' Sue explained, 'and half of all people over 85 are now being diagnosed with Alzheimer's.' If they don't find a cure, or at least a solid form of treatment, seniors could become a huge burden on society.

Someone in the class asked what we could do to improve our odds of avoiding Alzheimer's disease and other forms of dementia. 'The risks are higher for certain groups,' she told us, 'such as those with head trauma, diabetes and high blood pressure.' She explained that the "brain-heart connection" is significant, so take care of your heart to reduce your risk. And statistics show those of African-American and Hispanic origins develop Alzheimer's more often than Caucasians.

'Genetics only seems to be a factor in early-onset patients,' Sue told us, meaning those patients who develop the disease before the age of 65.

Well, genetics are in my favour—no one in my family had dementia, to my knowledge. I eat right, exercise regularly, and so far, I'm in good health. I'm sparking my brain to keep it in top shape, too.

Meanwhile, I'm writing a check and hoping they find a cure soon. Living until I'm 120 means I've got to beat the odds!

This column by Kathleen D Tresemer was previously published in *The Rock River Times* in June 2011.

■ Research update

National Task Group on Intellectual Disabilities and Dementia Practices

Dr Matthew Janicki, University of Illinois at Chicago, USA



Members of the National Task Group during a meeting to discuss the needs and concerns of people with intellectual disabilities affected by dementia

In early 2011, following the signing of the National Alzheimer's Project Act (NAPA) in the USA, the National Task Group on Intellectual Disabilities and Dementia Practices was formed. The overall goal of the Group was to feed into the efforts being undertaken in the USA under the National Alzheimer's Project Act and ensure that the concerns and needs of people with intellectual disabilities and their families, when affected by dementia, are considered as part of any national strategy.

The National Task Group, co-chaired by Dr Matthew P Janicki and Dr Seth M Keller, is composed of some 100 administrators, clinicians, academics, researchers, agency personnel, national organisation representatives, and family members from all over the USA.

Following a year of research and discussion, the group has developed a summary report of its findings. The 42-page report, *'My Thinker's Not Working': A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia*

to Remain in Their Community and Receive Quality Supports, is composed of background information and, alongside The National Dementia and Intellectual Disabilities Action Plan also contained in the report, offers recommendations for the improvement of services nationally as well as locally and suggests actions that can be undertaken by national, state, and local organisations, as well as governmental entities at the federal and state level.

The report concludes that:

- Most adults with an intellectual disability live in community settings, either independently or with support from families, friends and service providers; with advanced age, they may experience age-related conditions and diseases, including dementia.
- Epidemiological research has not arrived at reliable population counts of adults with an intellectual disability affected by mild cognitive impairment and dementia and more effort is needed to create a more reliable estimate of this population.

- Dementia has a devastating impact on adults with an intellectual disability as well as on their families, friends, housemates, and service provider staff who often provide key long-term support and care.
- Community services providers are facing a 'greying' of their service population, many of whom are affected by cognitive decline and dementia, and are challenged to provide the most effective and financially viable daily supports and long-term care.
- Primary care and support for adults with an intellectual disability affected by dementia can be primarily provided within the community and appropriate services can preclude institutionalisation.
- Providers are beginning to adapt small group homes for specialised community care and support for people with an intellectual disability affected by dementia.
- Professional staff are often ill equipped to help identify and support interventions that may be the most efficacious for adults with an intellectual disability affected by dementia.
- There is a lack of background knowledge and training in late life problems of adults with an intellectual disability among primary care health providers (including physicians, physician assistants, and nurses) in community practice.
- Specialised assessment and diagnostic resources are needed to help more effectively identify adults with an intellectual disability and dementia.
- A common screening instrument would be useful for the cognitive impairment review that is part of the new Affordable Care Act's provision for an annual wellness visit.
- Creating a national programme of training using workshops, webinars, and other teaching methods, would advance the knowledge and skills among workers and clinicians working with adults with an intellectual disability affected by dementia.

- Creating a national information and education programme for adults with an intellectual disability and family members would improve their understanding of dementia and potentially lead to earlier identification and acquisition of timely supportive services.
- Access to appropriate professionals and supportive services outside major urban settings needs to be improved; technology may play an important role in achieving this goal.
- State and local developmental disabilities' authorities could more constructively forecast and budget for supporting in-community care of adults with an intellectual disability affected by dementia.

The Report recognises that Alzheimer's disease impacts adults with lifelong intellectual disabilities mostly in the same ways as it does other people, but sometimes has a more profound effect due to particular risk factors – including genetics, neurological injury, and deprivation. The report also notes that it is important to recognise signs of dementia-related changes early, and identified an instrument particularly applicable to adults with an intellectual disability. With respect to community care, the report stresses the importance of supporting families who are the primary carers for adults with intellectual disabilities, and proposes the development and maintenance of a network of small, specialised dementia-capable neighbourhood-based group homes. The report also notes that although dementia has a devastating impact on all people – including people with an intellectual disability and their friends, families and the staff who may be involved with them as advocates and carers – that special efforts need to be undertaken to aid those disadvantaged adults with intellectual disabilities.

The Group has now begun work to produce educational materials, develop guidelines for care and supports, and is designing training sessions that will be held across the country over the coming year.

Information about the National Task Group and access to its documents, including its report and action plan, is available at www.aadmd.org/ntg

10/66 Dementia Research Group

Mild cognitive impairment is associated with disability and neuropsychiatric symptoms

Dr Rob Stewart and the 10/66 Dementia Research Group presented their latest paper, *Prevalence, distribution, and impact of mild cognitive impairment in Latin America, China and India: a 10/66 Population based study*, in PLoS Medicine in February 2012.

In low and middle income countries, mild cognitive impairment is consistently associated with higher disability and with neuropsychiatric symptoms but not with most socio-demographic factors.

The 10/66 Dementia Research Group interviewed roughly 15,000 people aged over 65 years who did not have dementia in Cuba, Dominican Republic, Peru, Mexico, Venezuela, Puerto Rico, China, and India, all low and middle income countries.

Participants also completed standardised assessments of their mental and physical health and their cognitive function and the researchers also interviewed relatives and carers for further details about any memory loss or other decline in cognitive function or the presence of any neuropsychiatric symptoms.

Then, by using a clinical framework and a statistical model, the authors found that mild cognitive impairment with related memory problems was associated with disability, anxiety, apathy and irritability but not with depression.

Increasing age or former education level did not seem to be linked, but the authors found that men had a slightly higher prevalence of mild cognitive impairment than women. Furthermore, the prevalence of this

type of mild cognitive impairment ranged from 0.8% in China to 4.3% in India.

The authors say: 'This is one of the first studies, to our knowledge, to investigate the prevalence of [mild cognitive impairment with related memory problems] in [low and middle income countries], where the large majority of older people and people with dementia currently live.'

They continue: 'Differences in prevalence between countries were marked and ranged from 0.8% (China) to 4.3% (India), that is, greater than fivefold variation. After direct standardisation for age, gender, and education, using the whole population as the reference, these differences were not markedly attenuated.'

The authors conclude: 'Further evaluation is needed of the associations with disability and neuropsychiatric symptoms since our findings do suggest higher than expected comorbidity and there are large absolute numbers of older people with [mild cognitive impairment with related memory problems] in these rapidly ageing and populous world regions.'

The full paper can be viewed on the PLoS Medicine website at www.plosmedicine.org/home.action

■ News

WHO to launch global dementia report

The World Health Organization will launch a new report highlighting the current state of dementia services and policy worldwide on 11 April.

The report will be launched to coincide with World Health Day on 7 April, which will focus specifically on ageing and health this year.

ADI has played an active role in the development of the report with contributions from Daisy Acosta, ADI Chairman, and Executive Director, Marc Wortmann, as well as a number of ADI member association representatives from across the world.

More information about the report and the launch will appear in the next issue of *Global Perspective*.

For more information about World Health Day visit www.who.int/world-health-day

Alzheimer Award

The winners of the 4th ADI and Fondation Médéric Alzheimer Award for psychosocial interventions have been decided. A high quality of applications were received for both the best intervention and most promising intervention categories this year. The winners of both awards will be announced at ADI's Conference Dinner on Friday 9 March at The Painted Hall, London, during ADI's International Conference.

For more information about the award and the previous winners, visit www.alz.co.uk/alzheimers-award

Puzzle with Me in major US retailer



Jane Snyder, founder of *Puzzle with Me*, at a Walgreens store in Scottsdale, Arizona

Puzzle with Me is a range of puzzles for individuals who are affected by dementia, both directly and indirectly. Introduced at the ADI International conference in Toronto, Canada in March 2011, *Puzzle with Me* is now being sold in 107 Walgreens stores across the United States of America. This product is a major breakthrough in the consumer industry to raise awareness and change the face of dementia. For every puzzle purchased, a donation is made to ADI in support of its efforts to discover more about dementia and continue to work with its members worldwide.

Jane Snyder, CEO and founder of *Puzzle with Me*, has a mission to find tools and solutions for carers, family and friends to create quality time and reconnect with people with dementia. Her own mother, who had Alzheimer's disease, passed away in November. As a carer, Jane understands the need to share quality experiences with dignity and respect that create a one-on-one connection with loved ones affected by the disease.

Throughout her arduous journey, Jane has had the opportunity to meet many individuals who console and care for people with dementia, furthering her compassion for carers. She is driven by her own personal experience, as well as the motivation she sees in others.

Recently she met a woman of forty-four years old who was diagnosed with early-onset Alzheimer's disease. Confused and distraught, this woman confided in Jane about her fears and uncertainty. Jane was able to, not only console her, but also introduce the idea of finding solutions to solve it ... together.

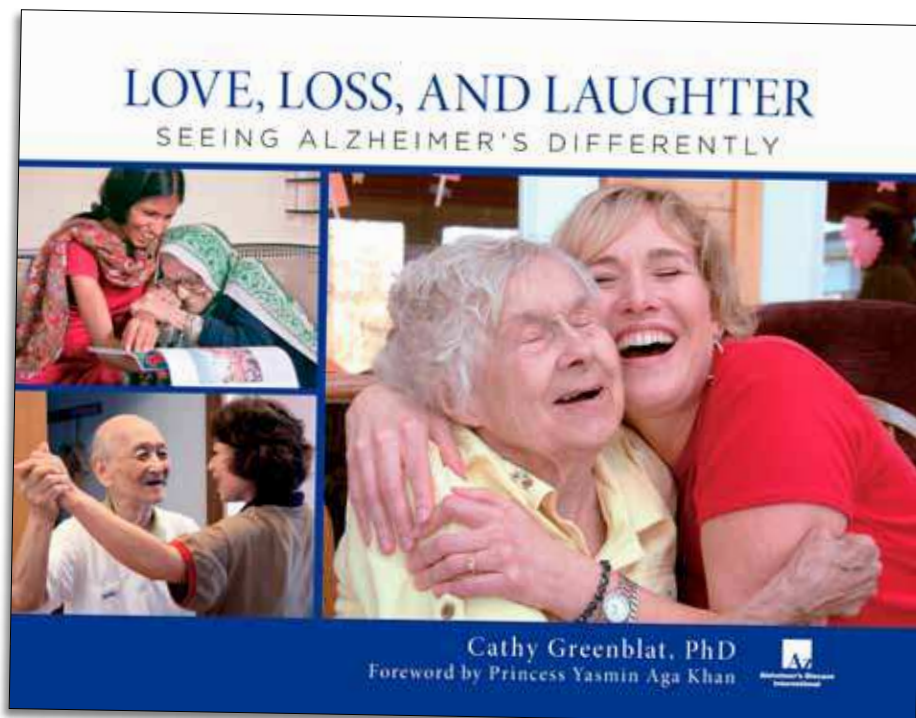
For more information and to view the range of *Puzzle with Me* products, visit the website at www.puzzlewithme.com. Jane will also be at ADI's International Conference in London from 7 to 10 March as an official exhibitor. Visit the booth to share your experiences and learn more about *Puzzle with Me* and Jane's mission.

■ Review

Love, Loss, and Laughter

Cathy Greenblat, a photographer based in France, has dedicated the last ten years of her life to reducing the stigma associated with dementia worldwide. The results of her pioneering cross-cultural photographic project are gathered in an important new book *Love, Loss, and Laughter: Seeing Alzheimer's Differently*. The book is a companion to exhibitions that have been touring for the past two years to prestigious venues in locations including Washington DC, Glasgow, Toronto, Nice, Madrid and Salamanca.

The book, which is endorsed by ADI, presents more than one hundred of Cathy's photographs taken in homes, memory clinics, day programmes, and residential centres in the USA, Canada, Japan,



France, India, Monaco and the Dominican Republic. Cathy melds her images and text with thoughtful quotations and excerpts from care partners, medical practitioners, social care providers, researchers, and people living with dementia diagnoses that present a wealth of practical, upbeat information and advice.

Cathy, who has provided photographs for all three World

Alzheimer Reports and numerous other ADI and member publications, will be present at the Opening Ceremony of ADI's 27th International Conference in London on 7 March for the launch of the book. The USA launch takes place in New York on 14 March.

If you are interested in hosting or sponsoring the exhibition or you have a good connection to a foreign publisher please contact info@alz.co.uk to discuss how you can be involved. Additional invitations and suggestions are also welcome. The book is well-priced and bulk purchases of 50 or more copies for training and special events are available from the publisher.



Queen Sofia of Spain visited the exhibition in Salamanca

Delegates attending ADI's International Conference in March can visit Cathy's exhibition at University College London, UK from 5 to 16 March. It will be at Pace University, New York, USA from 15 March to 28 April and at the Palais des Nations in Geneva from 3 to 16 April. For more information about the book and exhibition visit www.LoveLossAndLaughter.com

**In the next issue of
Global Perspective
June 2012**

- **ADI conference 2012 review**
- **Launch of the WHO report on dementia**
- **A look ahead to the first international World Alzheimer's Month**