



**Alzheimer's Disease  
International**

*The global voice on dementia*

30 YEARS

June 2015  
Volume 25 No. 2

# Global Perspective

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

## Care, Cure & the Dementia Experience - A Global Challenge 30<sup>th</sup> International Conference of ADI

**ADI marked its 30th anniversary conference this year in Perth, Australia with over 1100 delegates in attendance from around the world. Alongside professional and family carers, researchers, clinicians and Alzheimer association staff and volunteers, there were more people with dementia than at any previous conference.**

The first plenary presentation was by Edie Mayhew, who is living with dementia having been diagnosed at age 59, and her partner of 30 years, Anne Tudor, who spoke about their "bitter-sweet" journey with younger onset dementia.

Dr Serge Gauthier, from Montréal, Canada, outlined the latest developments in diagnosis and treatment, and Prof Martin Prince from King's College London spoke about risk reduction and the global nature of dementia in an ageing world, with prevalence being similar across low and high income countries. **CONTINUED ON PAGE 4**



**Conference delegates were welcomed by Dr Richard Walley on behalf of the Nyoongar people. The welcome was followed by an aboriginal dance performance.** Courtesy of Andy Romano – propertyDIGITAL

## WHO hosts dementia conference

**Government ministers and senior officials from 80 countries across all world regions attended the World Health Organization's First Ministerial Conference on Global Action Against Dementia in March.**

The two-day landmark event, held in Geneva, Switzerland, was hailed as the largest, highest level event so far to be organised by the WHO's Department for Mental Health and Substance Abuse with attendance of almost 400 individuals. In a statement made during the event, WHO Director-General Margaret Chan commented on the "full house" and stated "I seldom see meetings with such a big gathering". As well as government ministers, 45 non-governmental organisations (NGOs) were in attendance alongside more than 80 foundations, academic institutions and research centres.

The event aimed to encourage a coordinated effort by each country to address issues relating to dementia care, policy and research. Martin Prince, coordinator of the 10/66 Dementia Research Group and the Global Observatory for Ageing and Dementia Care, presented the latest prevalence figures at the opening of the event and was followed by the UK's Department of Health and World Dementia Envoy Dennis Gillings.



**CONTINUED ON PAGE 4**



## Alzheimer's Disease International

*The global voice on dementia*

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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 31 July 2015.

### 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](mailto:info@alz.co.uk)  
Web: [www.alz.co.uk](http://www.alz.co.uk)

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## Editorial

**Wendy Fleming**, ADI Honorary Vice President and former Vice Chair



**In the words of the song "Let's start at the very beginning..." Before 1999 I was unaware of ADI. This changed when I travelled that year to the ADI conference in Johannesburg in the role of Chair for the ADI conference to be held in Christchurch, New Zealand in 2001.**

When I walked into the ADI Council meeting I was completely overwhelmed! Never before had I been in the presence of such an array of people from all over the world with their national flags around the wall – I thought I had arrived at the United Nations!

After attending the conference and witnessing the commitment to dementia of all involved, I decided that I wanted to be involved with this unique organisation way into the future.

And so it was to be – elected to the Board 2004 – elected Vice Chair 2009 – 2015. Over these years I have been fortunate to work alongside a group of amazing people - 5 Chairs, fellow Board members, 2 Executive Directors and ADI staff, all very different but all with one common denominator – an unwavering dedication to ADI and the ideals that this organisation stands for.

As they say "from a small acorn the mighty oak tree grows" and so it is for ADI. From a membership of 4 this international federation of Alzheimer's associations has grown to over 80 today.

But there are challenges ahead. The outstanding success of ADI's global advocacy and raising of global awareness has come at a cost as the demand for support and services has increased and this requires funding. Securing funding for not-for-profit organisations is not easy so it becomes a fine balancing act.

But the one factor that remains certain in this scenario is that the number of people affected by dementia will continue to rise.

Under the leadership of Glenn Rees and with the support of the new Board and management team, I am confident that ADI will plan well so that the resources available are used wisely and as they plan I know they will listen to the voices of people with dementia and those who care for them.

I thank you all for your support and friendship over the years and I look forward to meeting you in the near future in my new role, one that I am immensely proud of.

*"Alone we can do so little; together we can do so much"*

Helen Keller (1880 - 1968)

## Events

2 – 4 September 2015

**25th Alzheimer Europe Conference**

**Ljubljana, Slovenia**

Web: [www.alzheimer-europe.org/Conferences](http://www.alzheimer-europe.org/Conferences)

18 – 23 July 2015

**Alzheimer's Association International Conference (AAIC)**

**Washington, D.C., USA**

Web: [www.alz.org/aaic](http://www.alz.org/aaic)

15 – 17 October 2015

**8th Iberoamerican Congress on Alzheimer's Disease**

**Rio de Janeiro, Brazil**

Web: [www.aibbrasil2015.com](http://www.aibbrasil2015.com)

15 – 18 October 2015

**9th International Congress on Vascular Dementia**

**Ljubljana, Slovenia**

Web: <http://icvd.kenes.com>

18 – 21 November 2015

**17th Asia Pacific Regional Conference of Alzheimer's Disease International**

**Manila, Philippines**

Web: [www.aprc2015-philippines.com](http://www.aprc2015-philippines.com)

21 – 24 April 2016

**31st International Conference of Alzheimer's Disease International**

**Budapest, Hungary**

Web: [www.adi2016.org](http://www.adi2016.org)

VISIT [WWW.ALZ.CO.UK/EVENTS](http://WWW.ALZ.CO.UK/EVENTS) FOR MORE CONFERENCES AND ANNOUNCEMENTS

## ■ News

### ADI's new Elected Board

**Chairman** Glenn Rees, Australia

**Vice Chairman**

Dale Goldhawk, Canada

**Treasurer**

Andrew Ketteringham, UK

**Medical and Scientific Advisory Panel Chairman**

Serge Gauthier, Canada

**Board members**

Faraneh Farin, Iran

John Grosvenor, UK

Mariella Guerra, Peru

Markus Löffström, Finland

Birgitta Martensson, Switzerland

Gerald Sampson, USA

**President**

Princess Yasmin Aga Khan, USA

**Honorary Vice Presidents:**

Daisy Acosta, Dominican Republic

Henry Brodaty, Australia

Wendy Fleming, New Zealand

Nori Graham, UK

Brian Moss, Australia

Jacob Roy, India

ADI wishes to thank Jacob Roy, Wendy Fleming, Carolyn Popham and Robert Yeoh for their hard work on the Elected Board. ADI also would like to thank Lynda Hogg who recently stepped down from her role on the Board. Lynda's contribution, representing the voice of people with dementia, has been invaluable and she will be greatly missed by the ADI Board and staff.

### Regional Caribbean conference

In partnership with our member, Stichting Alzheimer Curaçao (SAC), ADI hosted the second Regional non-Latin Caribbean Conference from 27 February to 1 March in Willemstad. The event marked SAC's 15th anniversary and incorporated an ADI workshop on public policy.

As many as 18 island/country representatives attended the ADI workshop that included ADI members, developing members and other country representatives from the Caribbean. A representative from the Pan American Health Organization (PAHO) presented a draft of the regional dementia action plan for the Americas.

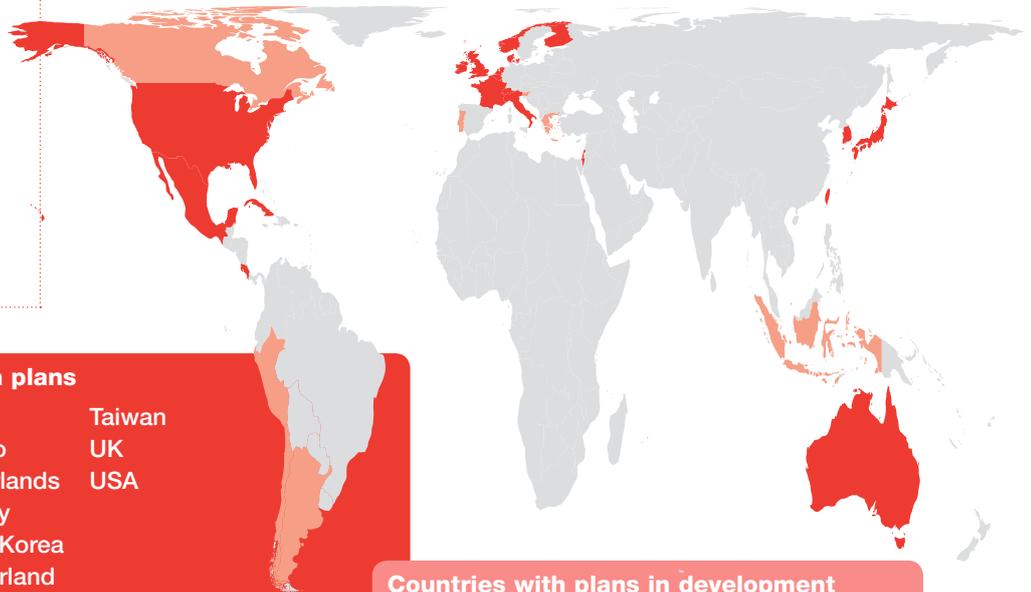
More than 220 delegates attended the conference, which opened with a review of the current status of dementia across the islands. Additional topics covered during the conference included the effects of dementia on society, its financial consequences and the future of dementia in the Caribbean.

ADI Deputy Executive Director Johan Vos, together with SAC members attended meetings with the Curaçao Government to garner support for a national dementia plan. As part of the official conference programme, SAC presented their draft National Dementia Action Plan to Curaçao's Minister of Social Affairs and Minister of Public Health.

ADI wants to congratulate Haydée Clementina and her team at SAC as well as ADI Regional Representative for the Caribbean drs Raymond Jessurun for organising and hosting the Caribbean regional conference. It was a very successful and interesting programme.

### National dementia plans update

On 2 April, Malta became the 21st country to launch a national dementia plan and the first to provide a dementia-friendly version. A further eight countries have plans in development and, with ADI member associations regularly approaching their governments about making dementia a priority, it is likely that many more will be in development soon.



#### Countries with national dementia plans

Australia	France	Malta	Taiwan
Belgium	Ireland	Mexico	UK
Costa Rica	Italy	Netherlands	USA
Cuba	Israel	Norway	
Denmark	Japan	South Korea	
Finland	Luxembourg	Switzerland	

#### Countries with plans in development

Argentina	Chile	Peru
Austria	Greece	Portugal
Canada	Indonesia	Slovenia

## ■ Cover Stories

### 30th International Conference of ADI CONTINUED FROM COVER

People living with dementia were heavily involved in the programme, speaking in several plenary and parallel sessions. Kate Swaffer, who is living well with Younger Onset Dementia, spoke about her work in developing and consulting on dementia friendly community projects around Australia and globally. She said a dementia friendly community was about respect, equality, accessibility, autonomy, inclusion and supporting the disAbilities of people living with dementia.

Elizabeth Gelfand Stearns, one of the co-producers of the award winning *Still Alice*, spoke about how the film had been designed to shine a light on Alzheimer's disease, but said it had not been an easy process. The original book by Lisa Genova had been rejected by 35 publishers and was eventually self-published, before becoming a bestseller.

Senator the Hon. Mitch Fifield, the Australian Government Assistant Minister for Social Services, opened day two of the conference.

A moving play from New Zealand about dementia, *The Keys are in the Margarine*, marked the final plenary presentation.

Two NCD Dialogues on shared risk factors and NCDs (non-communicable diseases) in the workplace were held in collaboration with the NCD Alliance. There was a consensus on the need for dementia to be integrated into global and national public health programmes alongside other major NCDs.

The conference also featured a vibrant exhibition area which included a dementia friendly Apartment for Life, a Healthy Brain Precinct, a bush garden and an interactive art studio, alongside care providers, Alzheimer associations and the display of poster presentations.



**ADI Executive Director Marc Wortmann and former Chair Jacob Roy cut the ADI 30th anniversary cake at the conference**

The #ADI2015 hashtag gained over 3 million social media impressions over the course of the conference, and 45 news stories about conference presentations appeared across TV, radio, newspapers and online news sites in Australia. Many presentation slides from the conference are now available on our website at [www.alz.co.uk/ADI-conference-2015](http://www.alz.co.uk/ADI-conference-2015).

ADI's thanks go to Alzheimer's Australia WA, Alzheimer's Australia, committee members, MCI, all of the sponsors, exhibitors, presenters and participants for contributing to a great conference.

### WHO hosts dementia conference CONTINUED FROM COVER

Hilary Doxford from the UK, Michael Ellenbogen from the USA and Kate Swaffer from Australia were present at the event and represented the voices of people with dementia, sharing their views on what governments' priorities should be. ADI's Executive Director, Marc Wortmann, added to this by reading a statement on behalf of 42 ADI member associations and NGOs, outlining areas for consideration.

During the meeting many government ministers described their ongoing national efforts to improve the lives of people with dementia and their carers. It was announced at the event that the government

in Luxembourg had made a commitment that dementia will be a priority of the European Union when it takes over Presidency in July.

A global consensus on clinical trials was reached during the event and it was announced that the UK government, Alzheimer's Research UK and pharmaceutical companies would commit to a US\$100 million fund for dementia research. The call to action, drafted and circulated to all ministers ahead of the event, was adopted and the process for implementation will be decided during follow-on meetings. Areas highlighted in the call to action include: promoting a

better understanding of dementia; collaboration on and advancing research; delivery of health and social care; and supporting the development of national dementia plans, particularly in low-income countries with fewer resources.

As part of the event, a Global Dementia Framework was developed, allowing countries and organisation to share and promote their commitments on dementia. For more information about the Global Dementia Framework visit <https://globaldementiaframework.wordpress.com/>

## Member profile

# Alzheimer Scotland



**Alzheimer Scotland is Scotland's leading dementia charity. We are a membership-based organisation with about 7,000 members, and have approximately 1000 staff and 700 volunteers.** Our core mission is to *make sure that no one goes through the experience of dementia on their own.* To achieve our mission we have two main goals which drive all of our work; *Being the foremost provider of information and support services for people with dementia, their partners, families and carers throughout Scotland, and Being the leading force for change at all levels of society, protecting and promoting the rights of people with dementia, their partners, families and carers.*

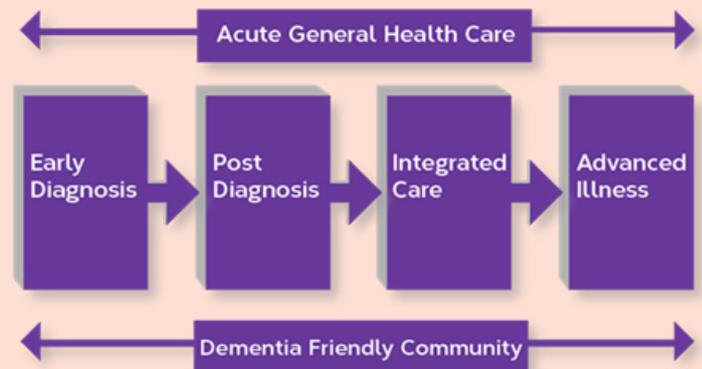
We have over 60 sites across Scotland, which provide care services and support, including: day activities; home-based care; one-to-one support; and carer information and training. In addition we make a very significant contribution to supporting people living with dementia across Scotland. We spend over £4million per year of fundraised income to fund a number of key initiatives. In partnership with the Scottish Government, we fund Alzheimer Scotland Dementia Nurse Consultants who work to influence change and improvement at an executive level within Scotland's National Health Service. We also fund a network of Dementia Advisors across Scotland and a free 24 hour Dementia Helpline, both of which provide crucial support to people with dementia, their families and carers. We also fund a Dementia Research Centre and Brain Tissue Bank in Edinburgh and support a Centre for Dementia Policy and Practice at the University of the West of Scotland. In recent years, we have funded and opened

several Dementia Resource Centres (with more planned). Our dementia resource centres provide a community resource where people can drop in and talk to our staff and receive information about dementia. They play an important role, alongside our dementia friendly communities and Dementia Friends initiatives, in breaking down stigma and the fear of dementia by bringing dementia into the high street.

Listening to experiences of people living with dementia is extremely important to us. As well as listening to the experiences of our members and those who use our services we also support, fund and work in partnership with the Scottish Dementia Working Group and our National Dementia Carers Action Network.

Alzheimer Scotland has a clear vision for the change required if people with dementia and their partners, families and carers are to have access to timely, skilled and well co-ordinated support, care and treatment, from diagnosis to end of life. Alongside that, we must continue work to improve the care of people with dementia in hospital, and we must support our communities to become more supportive of people with dementia.

We recently launched a multi-faceted awareness campaign to break down the stigma, fear and negative perceptions of dementia. The campaign is aimed at encouraging families to talk more openly about dementia so



that they are more confident in seeking help earlier. We are also currently developing an advanced stage model for the highest quality of care and support of people with dementia as they go through transitions in the more advanced stage of the illness including end of life care. We will work with the Scottish Government and other partners to include a commitment to test the model in Scotland's third National Dementia Strategy due in 2016. Our work in these areas will build on the post diagnostic support commitment and 8 Pillar model of integrated community support so that people living with dementia receive the highest quality of care, support and treatment at every stage of the illness through seeking and getting a diagnosis, post diagnosis, living well with dementia for longer and end of life care.

On the 1 June 2015 we will be hosting our annual Dementia Awareness Week Conference in Glasgow. The 2015 conference theme is *Global Progress; Local Impact* and we have an excellent programme speakers from across, Scotland and beyond including Glenn Rees the recently appointed Chair of Alzheimer's Disease International.

For more information about Alzheimer Scotland visit [www.alzscot.org](http://www.alzscot.org)

# Members' forum

ADI members: do you have news to share with the global dementia community? Please contact us - [info@alz.co.uk](mailto:info@alz.co.uk)

## AUSTRALIA

### Discussing sex and ageing

Alzheimer's Australia Vic will host an international conference centred on the topic of older people and sex, relationships and intimacy later this year. The event, which will take place on 8 and 9 September in Melbourne, aims to break down taboos and stereotypes and consider the key role that sex and intimacy play in quality of life.

Under discussion will be subjects such as the general lack of provision for clients in aged care facilities to be intimate with their partners, safe-guarding people with dementia from sexual abuse, and the unique challenges that the combination of sex and dementia presents. Speakers at the event will include medical health, aged care and education professionals alongside government representatives. Registration for the conference is open to delegates from across the world and, for those unable to attend, online discussion will take place prior to and during the event on Twitter using #LTAS2015.

For more information about the conference and to register visit [www.ltas2015.com](http://www.ltas2015.com)



Relationships and Intimacy as We Age  
Melbourne 8–9 September 2015



## NEPAL

### Appeal following earthquake



ADI staff have been in frequent contact with staff at the Alzheimer's and Related Dementia Society of Nepal (ARDSN) since the devastating earthquake on 25 April and the second on 12 May. While everyone at ARDSN is safe, efforts are underway to support people with dementia and their families in the affected areas with the very few resources that remain. ARDSN became a member of ADI just last year and had only recently started to raise awareness and provide training in the country.

Prior to the earthquake, ARDSN had hosted a national dementia workshop for government ministers and non-governmental organisations. The aim of the meeting was to take the first steps towards establishing a Nepal Dementia Action Alliance to develop a Fight Dementia Action Plan. In attendance at the workshop were ADI's Regional Director for the Asia Pacific Francis Wong and Alzheimer's Australia Vic staff Ann Reilly and Amelia Suckling alongside representatives from Nepal's Ministry of Health and Ministry of Women, Children and Social Welfare. Various issues were raised at the workshop, such as the lack of awareness, diagnosis and support within Nepal.

Understandably, any developments resulting from this event will now be set aside and ADI is now collecting donations internationally to support ARDSN's efforts to assist people with dementia and their families. If you are able to contribute financially please visit [www.alz.co.uk/donate](http://www.alz.co.uk/donate). Any donations made until mid-June will be considered to be donations for ARDSN unless ADI is notified otherwise.

## IRELAND

### Campaign to replace Lunacy Act

On 1 April, The Alzheimer Society of Ireland collaborated with more than 15 non-governmental organisations in the country to campaign for the replacement of the 1871 Lunacy Act. The campaign, Fool Me Once, was launched to coincide with the tradition of April Fools' Day while also marking the 8th anniversary of Ireland signing the United Nations Convention of the Rights of Persons with Disabilities on 30 March. Attempts to replace the Act, which refers to people as 'idiots', 'lunatics' and of 'unsound mind', have failed in the past due to changes in government, but a promise to change the law and to enact an Assisted Decision Making Bill has not yet been actioned.

For more information about the work of The Alzheimer Society of Ireland visit [www.alzheimer.ie](http://www.alzheimer.ie)

## ■ Dementia International Alliance update



Support and Advocacy: Of, by and for people with dementia

# DAI started as a dream

*In a new regular feature, Dementia Alliance International (DAI) share their latest news and successes*

The recent ADI and Alzheimer's Australia joint conference in Perth was historical for a number of reasons. It was the 30th anniversary of ADI's conferences, we had the largest number of delegates ever to attend a dementia conference in Australia, and I believe most importantly, almost 10% of the delegates were people with dementia from around the world, also with more than 10% of family carers in attendance. Finally, each day included a person with dementia as a plenary speaker, and two Australians Edie Mayhew who lives with dementia, and her partner Anne Tudor opened the conference on day 1, also representing the Lesbian, Gay, Bisexual, Transgender, Intersex and Questioning community. They gave a professional and poignant speech *Our Bitter-Sweet Journey with Younger Onset Dementia*. Helga Rohra one of our Board members from Munich presented on day 2 on her life living with dementia, a deeply personal account, with highlights of the many things she believes need to change, and her key message being: "just include us". I was honoured to present on day 2 on what a dementia friendly community really means to people with dementia.

A guest writer on my personal blog (<http://kateswaffer.com/2015/04/27/inclusion-its-that-simple>) said "**a diagnosis of dementia does not have to mean your life ends**, and nor should it."

This is absolutely the message I wanted to leave delegates with; that many more people with dementia can fully participate for much longer than the public perceptions about us suggest, with the appropriate disability supports in place. In fact, without including us at every level and in every conversation about us, organisations, communities, cities, towns and countries will never be dementia friendly.

The mantra "nothing about us without us", which began in the disAbility sector about 30 years ago, taken on in 2000 by DASNI and then the Scottish Dementia Working Group, is finally becoming a reality. It is no longer just a distant dream.

Our global group Dementia Alliance International, an advocacy and support group exclusive to people with dementia, again had a stand in the exhibition hall of the conference, and sponsored a number of people to attend. This group is, with the collaboration and support of ADI, the peak body globally for people with dementia. This comment also made on my blog anonymously also sums us up: *Don't all of a sudden think a person with dementia can no longer do anything, or don't start talking about the*



**DAI members with their exhibition stand at the recent ADI conference**

*person like they are no longer there – talk to them, talk with them – treat them with respect and INCLUDE THEM!*

Dementia Alliance International looks forward to our continuing work and collaboration with ADI, and to increasing membership in countries all around the globe. We plan to produce publications on issues specific to people with dementia on topics such as communication and language, and to find regular funding to support our work. Without funding, we will be held back in what we can continue to do, and what we dream to achieve. People with dementia have spoken out in large numbers, about the things that matter to them. DAI started as a dream by many people with dementia, all of the founding members having varying versions of that dream, but it was driven by the desire for change, and the desire to increase awareness, education and most importantly, connecting with other people living with dementia all over the world. It is about people with dementia finally finding their voice, and being fully included.

People with dementia have an indescribable instant bond; we fully understand one another, and we really know what it is to live with dementia. Many of the people with dementia doing advocacy work on their own have now joined to work together with other DAI members. What we can't do alone, we can do together. Including us will improve the lives of people with dementia, and reduce stigma, discrimination, isolation and other negative experiences of dementia.

If you have a diagnosis of dementia and wish to become a member of Dementia Alliance International, join at [www.dementiaallianceinternational.org/membership](http://www.dementiaallianceinternational.org/membership). If you are a carer or professional working in dementia, read more about us on our home page. Anyone can subscribe to our newsletter or weekly blog via our contact form. Many of our members' ADI 2015 conference presentations can be seen on the Dementia Alliance International YouTube channel.

## Living with dementia

# Never miss an opportunity

Hilary Doxford, UK



Hilary with her dog Tilly

**I was diagnosed with early onset Alzheimer's disease in December 2012. I was 46 when I first sought a diagnosis but my GP sent me away and it was another 7 years of increasing frustration and disappointment at my declining abilities before I was diagnosed. Of course it was a life changing experience, but in some surprising and positive ways.**

I was never a public person, I was the person behind the scenes who could help my boss deliver his vision. I would never have foreseen me speaking at a national level, let alone European or International.

When diagnosed I wanted to know how long I'd be able to function relatively well without assistance – I was told maybe two years. Bit of a panic at the time but those two years have gone and I'm doing fine. Then I asked about clinical trials – no information readily available. So, having a background in research and management I joined the Alzheimer's

Society as a Research Network Volunteer. This led into media work, joining Alzheimer Europe's European Working Group of People with Dementia, the World Dementia Council and becoming a member of Dementia Alliance International (open to all people with dementia).

I have learned some valuable lessons since December 2012. Firstly, I no longer worry about getting things wrong, if nothing else dementia gives you the perfect reason for not being perfect and in fact not being perfect demonstrates the difficulties we have. Secondly, never miss an opportunity. My first failure was my first media experience which happened to be with David Cameron following the December 2013 G8 summit. It took me all my courage to ask my question, 'where's the money' in response to his quote that we 'need to treat dementia as the national crisis it is'. His reply, 'I don't want to sit here adding up numbers, I want to....' and I sat there nodding in agreement but thinking, I do want you to sit there adding up numbers, but I

hadn't got the guts to follow through. That day, I determined I would never miss an opportunity like that again. Thirdly, I continuously learn from the great advocates who have spoken before me and continue to do so, I realise that I have little to say that is novel or new, so I try to re-enforce those important messages that have already been said.

I know how privileged and fortunate I am in my various roles. I have ready access to the projects and initiatives that will help us all and I see real hope. When I was diagnosed, I was asked for three words to sum up my thoughts; they were 'fear, despair and hope'. Now I worry about what lies ahead, but fear is too strong a word. My despair has gone. I now have great hope that a cure, although still far off, is at least on the horizon and, until it arrives, the work that goes on to help us live as well as possible gives me reassurance.

So far, I've been lucky and my life with dementia has not been difficult. I have challenges but not struggles. For as long as I am able, I am determined that I will rule my dementia and not let it rule me. I hope I can extend that time through my volunteering activities which keep my brain active. I've made new friends, met so many inspiring people and I know who are the heroes; it is those who struggle on alone, the carers, the unsung volunteers who support us week on week. I intend to do all I possibly can to help those who are alone, misunderstood and so brave in battling on against this cruel disease without the help they not only deserve but are entitled to. My other great hope is that we can make the world a level playing field for people with dementia to give everyone access to the support, services and opportunities that are available to me.

## ■ Carer's story

# A 10 year journey *Keiko Matsushima, Japan, Winner of the ADI-Home Instead Carer of the Year Award*



Kenji and Keiko with ADI Executive Director Marc Wortmann, and Lauren Swann (second left) and Kevin Rawnsley (far right) from Home Instead

**M**r Kenji Matsushima became aware of something wrong with his memory at the age of 56, while working as a technical manager of a company. He and his wife Keiko went to a hospital to clarify his condition and he was diagnosed with Alzheimer's disease. They never thought that it would happen to them. It was a moment of dismay, despair, and tears.

The family decided that they would never speak the name of the disease to his company or the people surrounding them. They were fearful that, if they told, Kenji would lose his job and would be discriminated against, and their daughter's engagement and marriage would be impacted. They thought that dementia was a disease to be ashamed of. They attended an Alzheimer's Association Japan (AAJ) meeting for people with dementia and family carers and were advised that dementia was a disease that anyone can get and is nothing to be ashamed of.

However, Keiko still insisted on hiding the illness and asked other group members to keep her secret. Kenji's disease had developed gradually but somehow he got through his work until the age of 60, which is the standard age of retirement in Japan. Almost all of his colleagues could continue to work after 60, but he could not.

After retiring, Kenji had nothing to do and was bored indoors all day long. Then Keiko's mother got dementia and became unable to live alone. Keiko made her move to the family home to take care of her. To make things worse, Kenji and Keiko's mother did not get on well and they had frequent tiffs. It was very hard for Keiko to take care of two people with dementia at home, as well as working to support the household. Keiko had her mother move to a group home for people with dementia, where she was taken care of very well. She passed away there in peace last year.

The family kept Kenji's disease a secret for 10 years

after his diagnosis. Finally the time to break their silence came. The springboard was an AAJ signature collecting campaign against the Government reform plan for long term care insurance. Keiko had a critical feeling that if the reform plan went through, the services covered by Long Term Care Insurance would decrease and contributions and the self-payment burden would increase. She decided to get involved in the campaign as a family carer. AAJ knows it is essential to include the voices of people with dementia and family carers.

Keiko and Kenji went from house to house. Keiko described the disease and how important retention of the reform plan was for living well with dementia. In addition, she explained that dementia is not a challenge only for those living with it, but a challenge for everyone. To her surprise, everyone they visited was supportive and encouraged them. They collected 300 signatures and also created a network of carers in their community. Since then they have been invited to a dance group, a Japanese drum group and a table tennis club in their neighbourhood. They have been enjoying those activities.

After they announced Kenji's disease to the public, both Keiko and Kenji had changed. Both of them could feel at ease and energised to live with dementia. Their lives have been extended. They participated in a discussion on early onset dementia with the Ministry of Health, Labor and Welfare. Even Keiko could not believe the change in herself. The signature collecting campaign was a trigger for change, but there were many circumstances which had encouraged her, little by little, with support from surrounding people, such as AAJ members. Their daughter got married and their son-in-law said dementia was not something to be ashamed of. Keiko began to feel that they were not alone and that they had friends to share their happiness and difficulties.

Kenji's Alzheimer's is progressing, but now Keiko believes Kenji can live well with dementia.

## How associations help

# A haven in Sri Lanka B D K Saldin, Sri Lanka

I had read about the Lanka Alzheimer's Foundation and decided to pay them a visit because my wife Sheila had been diagnosed with dementia in 2006. I met Lorraine who gave me details of how the Foundation was run. The Activity Centre, which provided therapeutic activities for persons with dementia and respite for the carer was open from 9am to 3pm.

Due to the distance between Dehiwela (where we live) and Maradana (where the Foundation is located) I was faced with a problem. If I brought Sheila to the Foundation in the morning I would have had to go back to Dehiwela and return in the afternoon. Being an octogenarian and suffering from spondylosis of the lower back it would have been too tiring, so I gave up the idea.

In the meantime Eileen Dane, of Wanita Sri Lanka Melayu (WASLAM) told me how good the care was at the centre and how attendees were happy and enjoying their visits to the Centre. This encouraged me to pay Lorraine another visit and explain the challenges I faced. She came up with the brilliant idea of involving my two sons. I could drop off Sheila in the mornings and each son would have a turn once a fortnight to pick her up at 3. Once my sons agreed to help out, I registered Sheila to attend the Activity Centre.

There are no restrictions on the people with dementia. They are free to do as they wish. Some are more active than others. The volunteers make each one feel special. People are greeted on arrival and welcomed with warm hugs.

Sheila found it difficult to sit in one place and loved to walk around. This caused problems as she was fond of wandering. We had to lock the gate at home because of the risk that she may forget the way back.

She loved her visits to the Foundation because there were plenty of open spaces and she had the freedom to walk around as much as she pleased. She was a good



Sheila with Lanka Alzheimer's Foundation volunteers

dancer but due to my ailment we could not indulge in her favourite pastime. She enjoyed the music therapy sessions at the Activity Centre where she would sing and dance to her heart's content.

We could not get her to do anything at home as her attention span was very short but Katie, who volunteers at the Activity Centre, managed to coax her to participate in drawing and painting. Although Sheila and I were married for fifty nine years, I was not aware of this hidden talent in her. The volunteers at the Foundation had the ability to get the best out of her - they were making arrangements for Sheila to take an active part at the Christmas celebrations on the 5th of December. But alas it was not to be as Sheila passed away on the 24th of October.

Her favourite song was *Somewhere over the rainbow* and I can't help but think that she is now somewhere over there.

The last days of her life were made happy by volunteers at the Lanka Alzheimer's Foundation for which I owe them everlasting gratitude. I wish more people were aware of the dutiful service they provide for people with dementia and their carers. I appeal to the general public to continue to support their fund raising events generously.

For more information about the Lanka Alzheimer's Foundation visit <http://alzlanka.org>

## ■ Research update

# The 5-Word Test *Bruno Dubois*

Almost any brain damage/dysfunction can induce a memory complaint or a memory deficit. Therefore, a subjective cognitive impairment (SCI) complaint to the General Practitioner is frequent although the GP may not always know how to manage this clinical condition.

To better understand the diagnostic algorithm of SCI we must have in mind the physiopathology of long-term episodic memory. Episodic memory is the capacity to recall personal events that can be identified in time or in space. For instance: to recall one's last meal, its taste, smell, the conversation and state of mind during the meal. To be recalled, the stimulus (whatever it is: a list of words, sentences, stories, images, drawings, smells...) must go through three different and successive stages:

- The first one is registration (encoding) of the information to be recalled, which mainly relies on attention resources which facilitate the capture of information by the perceptual and sensory cortical areas (visual cortex for images, auditory cortex for verbal items...). This stage is impaired in conditions that may interfere with attention processes. In all these cases, there might be a recall deficit not because of a long-term memory problem but only because of registration impairment.
- The second step is storage of information to be recalled: after the perceptual and identification stages, the information is transferred to the hippocampus to be transformed into memory traces. In case of hippocampal lesions, such as in Alzheimer's disease, the perceived information can no longer be stored as memory traces in long-term memory. In such conditions, the information will be lost and cannot be recalled anymore: this feature corresponds to a genuine memory impairment.
- The last stage is retrieval of information to be recalled: this stage relies on the ability to activate strategic processes to recollect stored information. This process is directly related to the functioning of the frontal lobes. This is why retrieval abilities are decreased in frontal lesions, fronto-temporal dementias, subcortico-frontal dementias and in functional states such as depression or even normal aging where the activation of retrieval strategies is decreased and effortful. In these conditions, the recall performance will be decreased in relation to a retrieval deficit.

To summarise, memory disorders in everyday life can result from several causes such as attention disorders (depression, stress...), retrieval difficulties (aging) as well as genuine memory deficit due to Alzheimer's disease. The best way to disentangle the diagnostic problem is to assess memory with a test that: 1) controls that the information has been truly registered; and 2) that can help the retrieval.

This is the interest of the 5-W Test: after the presentation of the list of words, a link is proposed between each item and its semantic category ("tell me the name of the drink, of the vehicle..."). Therefore, it is possible to control that the subject has encoded all the words by providing him/her the corresponding cues for those items that they were not able to retrieve spontaneously. Having done that, it is now possible to study the memory performance in itself after a delay of 5 -10 minutes by asking the subject to recall the 5 words. If he/she does not recall all the words, the same semantic cues are used to facilitate the retrieval of these words and to exclude a storage deficit that characterises Alzheimer's disease. Therefore, the absence of normalisation of the recall performance, despite the facilitation procedures, indicates the existence of an amnesic syndrome of the hippocampal type, mostly in relation to an Alzheimer's disease.

The 5WT is simple (a sheet with 5 words), short (1 minute for the presentation and 1 minute for the recall after a delay that can be used for other investigations) and needs no expertise. Any memory problems, except the memory deficit of Alzheimer's disease, should be normalised by cueing (score of 10). If the total score is below 10, it may signify a hippocampal dysfunction and justify referring the individual to a specialist or to a memory clinic for further investigation.

## The APECS study

*The information below has been provided by Merck*

Alzheimer's disease is an irreversible, neurodegenerative disease with no existing treatments to slow or halt its progression. Currently, Merck is focusing on both symptomatic and disease-modifying treatments for Alzheimer's disease. An Alzheimer's disease brain contains two major abnormalities, amyloid plaques and neurofibrillary tangles. The amyloid hypothesis states that early in the disease process amyloid beta peptides begin to aggregate into amyloid fibrils and plaques in the brain and later trigger the development of tau-related neurofibrillary tangles, which cause neuronal degeneration, brain atrophy, and cognitive decline. Merck has developed MK-8931, a BACE inhibitor, which means it helps stop the BACE enzyme from producing amyloid beta peptides. By inhibiting the actions of the BACE enzyme, it may in turn help stop the formation of those amyloid plaque deposits and modify Alzheimer's disease progression.

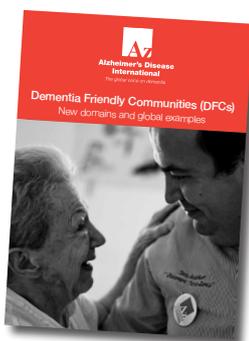
Merck is testing this hypothesis in studies involving approximately 1500 patients in 17 countries.

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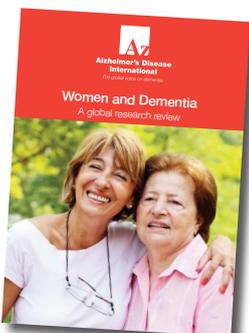
## ■ News

### New ADI publications

The term 'dementia friendly communities' has become more and more frequently used within the dementia movement in recent years. In response to this new and innovative phenomenon that has reducing the stigma surrounding dementia at its heart, ADI has developed a booklet containing examples from across the world of such initiatives. As well as charting the rise of dementia friendly communities, this publication also contains details of the common principals and tactics used in their development and implementation.

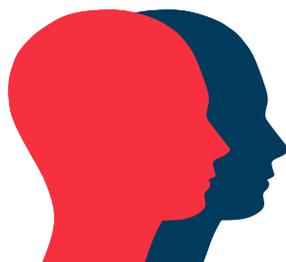


A new report, launched by ADI on 5 June, has revealed how women are much more likely to be affected by dementia than men. *Women and Dementia: A global research review* provides an overview of international research from all over the world, highlighting the need for a broader, evidence based approach to female-targeted dementia health programmes in low and middle income countries, where female-led family caring remains the predominant care model.



Both publications are available to view and download on the ADI website at [www.alz.co.uk/publications](http://www.alz.co.uk/publications)

## World Alzheimer's Month 2015



# World Alzheimer's Month

September 2015 will mark the fourth global World Alzheimer's Month, an international campaign to raise awareness of dementia. The theme for this year's campaign is *Remember Me* with the significance being two-fold; learning to spot the signs of dementia, but also not forgetting about loved ones who are living with dementia, or who may have passed away.

As part of the campaign ADI will be launching a new World Alzheimer's Month website, which will act as a platform for information and promotion of the campaign and the associated global activities and events. This site is expected to launch in June so do visit [www.worldalzmonth.org](http://www.worldalzmonth.org)

### World Health Assembly 2015

At the time of going to print, the World Health Assembly was taking place in Geneva, Switzerland. ADI representatives were present at the meeting to take advantage of opportunities for informal lobbying of improvements to dementia care and services worldwide. This year ADI hosted a side event alongside the NCD Alliance and the World Heart Federation with speakers including Jan Pitts who is living with dementia and Francesca Mangialasche who spoke about the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER).

### 25 years of your GP

In this issue we continue our series marking 25 years of *Global Perspective*.

**News from 1997:** In our summer 1997 issue, we shared news of the launch of our website. We also reported on the success of both our 13th International Conference in Finland and World Alzheimer's Day *Race against time* charter.

To read this and other back issues of *Global Perspective* visit [www.alz.co.uk/newsletter](http://www.alz.co.uk/newsletter)



### The APECS study CONTINUED FROM PAGE 11

The APECS study (MK-8931-019) will assess the efficacy and safety of MK-8931 compared with placebo in the treatment of amnesic mild cognitive impairment due to Alzheimer's disease, also known as prodromal AD. The primary study hypothesis is that at least one dose of MK-8931 is superior to placebo with respect to the change from baseline in the Clinical Dementia Rating scale-Sum of Boxes (CDR-SB) score at 104 weeks.

For more information on MK-8931, please visit [www.merck.com/clinical-trials](http://www.merck.com/clinical-trials) or [www.clinicaltrials.gov](http://www.clinicaltrials.gov). This trial can be found through the identification number NCT01953601.