



Alzheimer's Disease
International

The global voice on dementia

June 2016
Volume 26 No. 2

Global Perspective

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

31st International Conference of Alzheimer's Disease International



On 21-24 April, more than 800 people attended the 32nd International Conference of Alzheimer's Disease International in Budapest, Hungary, hosted by Alzheimer's Disease International and the Hungarian Alzheimer's Society. Commencing three days of events, representatives from member countries attended the annual ADI Council meeting, where a commitment was made to take a human rights-based approach to our advocacy efforts by mobilising around the United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD), with partner organisation Dementia Alliance International.

ADI welcomed two new members, the Alzheimer's and Related Disorders Association of Ghana and the Alzheimer's and Dementia Association of The Cayman Islands, and heard from Executive Director Marc Wortmann on the importance of ADI's attendance at the 69th World Health Assembly meeting in May.

The conference included a number of plenary sessions on the latest research and scientific knowledge, as well as ADI workshops on dementia friendly communities, strengthening Alzheimer associations and debates on the rights of people with dementia.

A number of member associations presented throughout the conference on their projects and commitment to global funding in dementia. Many talks and presentations were also given by people with dementia, who were well represented at the conference.

Events during the conference re-iterated ADI's commitment to supporting dementia awareness and funding in low and middle income countries and a strengthening of ADI partnerships with Dementia Alliance International and the NCD Alliance.

The 32nd International Conference of Alzheimer's Disease International will be held in Kyoto, Japan on 26-29 April 2017. Registration opens 11 July 2016 at www.adi2017.org

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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 25 July 2016.

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Correction

In the April issue of *Global Perspective*, the picture featured in the How associations help story was taken by Alzheimer's Disease Association Singapore, and not by TADA Chinese Taipei as the caption suggests. Our apologies for any confusion caused.

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Editorial

Marc Wortmann, Executive Director



ADI would like to extend warm thanks to all who took part in our conference in Budapest, Hungary. This year we not only welcomed new members to the ADI family but have formally adopted a rights-based approach to advocating for people with dementia. We have also strengthened our relationship with the World Health Organization, including attending the 69th World Health Assembly in May 2016.

As always, the ADI conference was a "family gathering" of the dementia movement and I was very pleased we could again increase the awareness of the rights and inclusion of people with dementia. This was the focus of two new reports, *Dementia Friendly Communities: Key principles* and *Global developments*, launched at the conference. These were followed by reports from Dementia Alliance International on human rights and dementia, and dementia friendly communities. I encourage you to read the reports and to make use of new dementia friendly communities content on the ADI website, where we're asking members and others to add new examples of initiatives worldwide.

In recent months, the policy work of ADI and member associations has achieved greater momentum for the establishment of national dementia plans. Plans have been developed in Austria, Indonesia, the Czech Republic and Greece and there is also increasing movement towards implementing plans in Argentina, Slovak Republic, Slovenia and others this year.

We are pleased to see steps that could result in a World Health Organization (WHO) resolution on dementia by May 2017, after ageing was discussed at the WHO Executive Board Meeting in May. The World Health Assembly earlier the same week also provided increasing visibility for Non-Communicable Diseases and included an amazing side event with a large number of Health Ministers speaking. On top of this, there was increasing demand for action on dementia in Europe, at the two-day European Union (EU) Presidency Conference, *Living well with(out) dementia*, marking the conclusion of the Netherlands' presidency this month.

Events

12 – 14 October 2016
8th Iberoamerican Congress on Alzheimer's Disease
Costa Rica
Email: info@aibcostarica2016.com
Web: <http://aibcostarica2016.com>

2 – 5 November 2016
19th Asia Pacific Regional Conference of Alzheimer's Disease International
Wellington, New Zealand
Email: admin@alzheimers.org.nz
Web: www.alzheimersconference.nz/

31 October – 2 November 2016
26th Alzheimer Europe Conference
Copenhagen, Denmark
Email: info@alzheimer-europe.org
Web: www.alzheimer-europe.org/Conferences/2016-Copenhagen

26 – 29 April 2017
32nd International Conference of Alzheimer's Disease International
Kyoto, Japan
Email: adi2017@mci-group.com
Web: www.adi2017.org

VISIT WWW.ALZ.CO.UK/EVENTS FOR MORE CONFERENCES AND ANNOUNCEMENTS

■ Meetings Roundup

Growing momentum for National Dementia Plans



Johan Vos meets Director of PAMI, Carlos Regazzoni and Dr. Facundo Manes in March.

Deputy Executive Director Johan Vos was invited by the Department of Social Services (PAMI) in Argentina this March, to offer advice on developing a National Plan on Dementia.

Director of PAMI, Carlos Regazzoni, and Dr. Facundo Manes from the Instituto de Neurologia Cognitiva, were instrumental in starting the process – including launching a strategy by October 2016 and consulting with community and interest groups on the development of the plan.

Our association in Argentina (ALMA) has been advocating for the national plan for many years, which will enhance support for an estimated 500,000 people with dementia.

Through the involvement and support of ADI, National Plans have since been adopted in both Indonesia and Greece, and further support for national plans is progressing in Chile where the plan is currently waiting on the political sign-off, before being launched later this year. In Uruguay, our member launched a Manifesto as the first step in developing a national Alzheimer's plan.

ADI's Executive Director Marc Wortmann and Deputy Executive Director Johan Vos held further meetings with Health Ministries in Slovak Republic and Mexico this May, where it is hoped there will be further progress on developing and implementing dementia plans.

Currently there are 26 countries that have a national dementia plan and others being developed. Having a national dementia plan means people affected by dementia should receive better services with health systems structured to deliver improved cost effective interventions.

You can access a list of national dementia plans on the ADI website, where we've provided links to the adopted plans and summary documents translated by ADI. The web page also contains a list of national and non-governmental strategies, as well as regional and sub-national plans.

EU Presidency Conference Living well with(out) dementia

ADI Executive Director Marc Wortmann and DY Suharya, newly appointed Deputy Regional Director of the Asia Pacific Regional Office, met with members of the World Dementia Council and local government in Amsterdam during the European Union (EU) Presidency Conference on dementia in May. The conference was held as part of the Netherlands' presidency of the EU and placed dementia on the urgent agenda for all European countries.



Marc and DY with Netherlands Minister of Care, Martin van Rijn at the EU Presidency Conference

Talks at the conference included the role of business, as well as policy leaders, in helping measure and shape innovative healthcare to tackle dementia in Europe. Other topics included the World Health Organization's *Vision for Dementia* and the launch of the Dutch campaign for a dementia friendly society by Martin van Rijn, State Secretary for Health, Welfare and Sport. Updates were also given on the MeetingDem and RHAPSODY projects supporting the Meeting Centres Support Programme and the evaluation of health and social care systems for people with young onset dementia.

Members' forum

AUSTRALIA

3D dementia-friendly home app



A dementia friendly home app has been developed by Alzheimer's Australia Vic, using 3D game software to improve understanding of the importance of environment to people with dementia and primary carers. Maree McCabe, CEO of Alzheimer's Australia Victoria, said that most people were not aware that people with dementia may experience spatial and visual challenges as well as the more commonly understood memory issues.

Based on principles such as reducing unhelpful stimulation and harnessing familiarity, the app provides a 3D model of the home with guidance for how to assist a person with dementia and ways of ensuring a person with dementia is able to extend the amount of time they can continue their life in their home, as part of the community. The app focuses on giving suggestions that are small and inexpensive, such as placing labels with pictures on cupboard doors and using colour to distinguish between items in a white bathroom or kitchen. More significant changes include installing motion sensors that turn lights on and off when people walk through the house and removing patterned wall or floor coverings.

The app was launched by Martin Foley MP, Victorian Minister for Housing, Disability and Ageing and is available for iPad and other tablets from the App Store and Google Play.

The Dementia-Friendly Home app was developed by The Deakin Software and Technology Innovation Laboratory (DSTIL) and Alzheimer's Australia Vic through funding by the joint Commonwealth and State Government Home and Community Care Program. Further information can be found at www.fightdementia.org.au/vic

UK

Four million Dementia Friends by 2020

The Dementia Friends initiative by Alzheimer's Society in the UK has attracted more than 1.5 million dementia friends in England and Wales. The hugely successful initiative has now been adopted in Canada, Nigeria and Mauritius, with many more countries launching their programme later this year.

In the UK, it includes the training of over 10,000 volunteer Dementia Champions, who go out into their communities and create Dementia Friends through delivering fun and informative Dementia Friends information sessions. Alongside the Dementia Friends programme, 160 communities in England and Wales have signed up to the Dementia Friendly Community recognition process and 232 local Dementia Action Alliances have been formed. Alzheimer's Society have also created Dementia Friendly resources for primary and secondary schools as part of its 'A Million Hands' partnership with The Scouts Association in the UK.

Alzheimer's Society plans to support 4 million Dementia Friends by 2020.

More information can be found on the Dementia Friends website: www.dementiafriends.org.uk



Members' forum

NIGERIA

Nigeria represented on the World Dementia Council

Nigerian Chief Kikelomo Lanionu Edwards was elected as a Full Member of the World Dementia Council at a meeting in London, where the Council was re-formed to include representation from all over the world.



The news comes after the *Dementia Friends* programme was launched earlier this year in Nigeria – only the third country to launch the initiative outside of the UK. The project will support a greater awareness of dementia, adding to an existing network of memory cafés and involvement in the *World Rocks against Dementia* campaign in March.

“Our relatives are now living well with their dementia, all thanks to a better understanding of the symptoms. We understand now that some dementias can affect behaviour, speech, mobility and reasoning abilities. It is not witchcraft but a disease that affects the brain.”

ITALY

Italy's first dementia friendly town

Federazione Alzheimer Italia has chosen Abbiategrasso, a town near Milan with 31,000 inhabitants, as a pilot for the first dementia friendly community project in Italy. The federation have identified a multi-disciplinary team of technicians, researchers and officials to lead the project, with the Golgi Cenci Research



Foundation, the Golgi Public Company for Service to the People of Abbiategrasso, the Federation of Palliative Care and the local municipality.

The project is currently drafting questionnaires for local stakeholders, including holding focus groups with people with dementia and carers. This will be followed by an analysis of ways to implement information-training events for merchants and law enforcement agents, on the cultural and social aspects related to the stigma of dementia and how to support dementia friendly awareness. The federation is also holding a number of activities through the voluntary associations in the area and the public library in order to increase participation of people with dementia and their families in the creation of the dementia friendly community.

The project slogan, *The strength of not being alone*, was chosen to reflect the sharing of a common effort to ensure that no one is left alone to deal with dementia.

NETHERLANDS

Dementie.nl supports carers to access help

Alzheimer Nederland have launched a responsive website, following the development of the Alzheimer Assistant App and website, to support people with dementia and their caregivers to record important information in a diary, access an online community for support and find guidance on common situations when dealing with dementia.



Since its soft launch in October 2015, more than 68,000 people have visited the website, which also includes a function to create a My Alzheimer Nederland account.

Find out more at <https://dementie.nl>



■ How associations help

Filming witchcraft and dementia in Namibia

Advocating for better understanding of dementia in Africa

Berrie Holtzhausen, Founder and CEO of Alzheimer's Dementia Namibia (ADN) spent time with a film crew from Hee Haw Films, examining the role that witchcraft plays in the awareness of dementia in Namibia. A documentary of their trip, *The African Witchfinder*, is planned for release early next year.

I believe that the cause of dementia in Africa may be defined differently to the rest of the world. My experience is that believing in witchcraft has a progressive and damaging impact on the brain. This belief is a natural part of society in Namibia, but presents a challenge to the awareness of dementia in particular.

A belief in witchcraft creates fear. As a young adult, you are afraid that someone may become jealous of you, because of your job or your relationships, and that their jealousy will cause them to bewitch you. Negative life experiences, such as bad health or losing your job confirm the superstitious belief that you are bewitched. When you grow older, you start fearing that you can be accused of being the witch or wizard who is bewitching other people in the family or community – that you are the cause of someone else's bad luck. You find yourself living in a very stressful and unhealthy atmosphere of social

dysfunction, mistrust and isolation.

'Every family has a witch'

For these reasons, I was very pleased that Mally Graveson and Toby Trueman of Hee Haw Films decided to film this aspect of dementia perception in Namibia – that witchcraft is often believed to be a leading cause of dementia in Africa. The crew were accompanied by Shara Johnson, a travel writer from the US who had previously written about tackling stigma through the work of ADN in Namibia. The crew and Shara

"I believe that the cause of dementia in Africa may be defined differently to the rest of the world."

spent two weeks in March visiting those that had been diagnosed as witches or bewitched, but who did not know what dementia was. Every family we spoke to had family members who displayed the symptoms of dementia and who were known as a witch – isolated and excluded from the rest of society.

I hope that this documentary will help ADN to inform the rest



The film crew and Berrie interview local residents about those accused of witchcraft. Image by Shara K Johnson

of the world about this factor in dementia, for I believe it might be as great a threat to the human brain as any biological disease, such as Alzheimer's, Lewy Bodies or Pick's Disease.

Creating awareness of dementia on the continent of Africa must fight these superstitions, and it is ADN's hope that after this film is released that there will be positive action to share in the awareness of dementia, and recognition of the harmful effects of the emotional fear and pressure witchcraft perpetuates.

ADN is excited to share this extraordinary story via the medium of film, and we are very grateful to Mally and Toby for all their hard work. We are also grateful to Shara who was instrumental in bringing us together.

You can read the full story of Shara's trip with Berrie at <http://skjtravel.net>

■ How associations help

Dementia experts provide radio counselling

Greek radio show connects public to wealth of information on dementia

Eileen Taylor, Secretary, Dementia Alliance International



Presenters of the show with grandchildren of people with dementia

Alzheimer Hellas and the Municipal Voluntary Radio of Thessaloniki, Greece (FM 100.6) have launched a radio programme titled All about dementia. The show, which airs 3 times a month, is presented by psychologists of Alzheimer Hellas, Eudokia Nikolaidou, Konstantina Karagiozi and Petrina Margaritidou.

The originality of this project is important, as it is the first time in Greece that there is a radio show with this design, where three experts on dementia inform and counsel listeners about such a crucial aspect of health. The programme includes recent information about dementia, conclusions of the latest research about therapy and different methods of prevention.

Health professionals, such as neurologists, psychologists, fitness instructors and care workers are invited to take part in the show, to communicate their knowledge and experience to listeners and inform them about symptoms and ways of coping with dementia. Carers and people with dementia are also regularly interviewed, providing an important public insight into dementia, by listening to their views on everyday life, thoughts and feelings.

The programme recognises the twin needs for information on dementia, on prevention and also on the importance of coping with and treatments for the disease, considering that people with dementia and carers deal with a range of emotional, practical, social and financial consequences.



Psychologists of Alzheimer Hellas and presenters of radio show, Petrina Margaritidou, Eudokia Nikolaidou and Konstantina Karagiozi

Alzheimer Hellas is a non for profit organization that was founded in 1995, by relatives of patients with Alzheimer Disease as well as by doctors of all specialties, including Neurologists, Psychiatrists and other experts. Today, Alzheimer Hellas operates 2 Day Care Centres in Thessaloniki and has over 4000 members.



■ Dementia Alliance International

Human Rights and Disability Rights news

Kate Swaffer, Chair, CEO & Co-Founder,
and **Professor Peter Mittler**, Human Rights Advisor, Dementia Alliance International

April 21st 2016 could be a watershed day in the history of people living with dementia. On that day the Council of Alzheimer's Disease International committed to a human rights-based policy, which includes access to the United Nations Convention on the Rights of Persons with Disabilities. This followed the work of Dementia Alliance International (DAI) previously, including the issue being put onto the global stage at the First WHO Ministerial Conference on Dementia in Geneva in March last year.

We're taking the first steps on a long journey towards a much fuller realisation of our human rights than people without dementia enjoy today.

Gerard Quinn, one of the founders of the Convention who is now working for a Convention on the Rights of Older Persons, put it like this:

"The UN CRPD is a mirror to society. It makes us face up to our own values and it forces us to acknowledge

the large gap that still exists between the 'myth system' of our own values... and the 'operations system' of how these values are dishonoured in daily practice. Thus the Treaty is a force for rationality as well as a vehicle for carrying these values squarely to the heart of the disabilities field. As with all mirrors, we can refuse to look into them; we can look at them but ignore their reflection or we can take notice of our reflection and commit to a process of change."



Kate Swaffer

DAI is now working with ADI and supporting ADI Council members to assist them in the work in their own countries to make this a reality for all people with dementia. You can read more about it on our website, which includes the position paper written by Neil Crowther, at www.dementiaallianceinternational.org/human-rights

Dementia Alliance International News

Online support groups

DAI continues to support members in six countries with weekly online support sessions. DAI member Eileen Taylor gave a presentation on the importance of the service at the ADI conference in Budapest. Her presentation is available on the DAI website.

Fundraising campaign

You have the opportunity to support DAI by donating. Every dollar, pound or euro you donate goes directly to supporting people with dementia to support themselves. *All* the money you donate helps people with dementia to live a better quality of life with a purpose and support from others also living with dementia.

Donations also help DAI continue its vital work on pursuing a human rights based approach for all people with dementia through the United Nations Convention on the Rights of Persons with Disabilities. *Your* donation ensures there will be 'Nothing about us, without us'.

Meeting of the Minds Webinar

A Meeting of the Minds webinar was held by Assoc. Professor Victoria Traynor, from the University of Wollongong on 'Driving and dementia', on the 25 May 2016. Victoria spoke of the development of a new 'Dementia and Driving Decision Aid' that is able to help tackle the feelings that can accompany retiring from driving in a person with dementia. Webinars are free for people with dementia and their carers. Slides of the presentation are available on the DAI website.

For more information, visit www.infodai.org

■ Carer's story

“Grandpa says stuff six times”

Emily Cryer, aged 21, speaks of her reasons for supporting Alzheimers New Zealand

When her grandfather passed away after living with dementia for ten years, Emily Cryer decided to ask her friends and family for donations to Alzheimers New Zealand instead of presents for her 21st birthday.

The story of Emily's Grandpa

My Grandpa Austin Cryer had Alzheimer's for 10 years. He was diagnosed in 2005. At first he still lived at his home in Taupo, 275km south of Auckland, with support from Enliven (Presbyterian support services). He then moved into a rest home in Taupo where he could get the care he needed.

But then he was forgetting stuff, and not in a good place. The day he wanted to withdraw \$20,000 cash from the bank for the supermarket shopping we knew something had to happen. We'd let him live as independently as possible for as long as we could, but finally we just had to move him.

“Watching Grandpa's struggle was one of the most heart breaking things my family and I went through. The disease meant we had to say goodbye to him before he was even gone from this world.”

When it became harder for Grandpa to live in Taupo, we moved him to Auckland, where we could better support him. The new home had a fantastic care group and there was one woman who visited him every day. She even spoke at his funeral. It was very moving.

My Dad and his brother spent all this time looking after him.

Emily's birthday

In New Zealand, the 21st birthday marks the coming of age, a person becoming an adult, so it is considered a milestone birthday.

As my own 21st birthday approached I began to take notice of my amazing life and how fortunate I had been with endless opportunity and support from my family and friends.

Both Alzheimer's and dementia have touched the lives of so many people I know. Two in three New Zealanders are affected by it in some way, including our family, so I got friends and relatives to give donations instead of presents. My Grandpa received incredible care which allowed him to live well with dementia, therefore I believe others deserve the same experience, to be cared for too and live as well as they can.

Alzheimers New Zealand is a federation of 21 local Alzheimer's organisations throughout New Zealand, that represent people affected by dementia at a national level by raising awareness of dementia, providing information, services and resources for people affected by dementia, and promoting research about prevention, treatment, cure and care of people affected by dementia.

Alzheimers New Zealand advocates for a world without dementia, and will be hosting the Alzheimers New Zealand and 19th Asia Pacific Regional Conference of Alzheimer's Disease International in Wellington on the 2-5 November 2016. Find out more at <http://www.alzheimers.org.nz>



Share your story

If you are interested in sharing your story in the *My perspective* section of the newsletter or have any comments, please contact us at info@alz.co.uk.



■ Living with dementia

The psychological impact of dependency issues on a single woman with FTD

Wendy Sanchez, Mexico, Dementia Alliance International member

I am a 73 year old American woman living independently (almost) in a small rural community in Mexico. I chose to move here after losing "life as I knew it" about 5 years ago. Prior to that I owned a house, rental property and two cars, worked four days a week and enjoyed a relationship, many friends and activities. The impact of losing all that was unimaginable. It overloaded my grief-processing abilities. Recently I was diagnosed with FTD, or Fronto Temporal Dementia.

Surrendering my driver's license (and therefore my job) catapulted me into depression. My identity, or so I thought, was so interwoven with all those roles; of landlady, homeowner, driver, career woman, competent grandmother and parent. I began to feel less than the rest of my friends and colleagues and family. I quickly learned taxis were unaffordable, the bus system was confusing and inadequate, and I hated to ask for help. I felt so ashamed to admit I needed assistance – whether directions when I got lost, reminders when bills became overdue, explanations to understand instructions, errands, doctor's visits or communication blocks, whether speaking or listening. I began to ride the bus with the homeless and disabled, confused and defensive. "I don't really belong here", I told myself. When I fell in public, I wouldn't let people help me up, and even got angry at the offer.

As my self-worth plummeted, I found myself avoiding social situations such as interactions with friends. I wanted to avoid embarrassing conversations for myself and others; those moments when I couldn't find a word or misunderstood what was said, for example. Excruciating at times. I began to doubt myself for the first time, and with that, fear became a daily visitor. It was crippling at times. I wanted a babysitter.

Other FTD symptoms came and some went: frequent falls, dropped objects, disinterest in creative projects I'd always enjoyed, unsafe stove practices and unwise decisions, especially around money. Even though

I'd suspected my diagnosis for more than a year, I still went into complete shock when it was confirmed by testing.

I was terminal and I was alone. My heart felt broken; I just wanted to be held by a caring person until the feeling passed. I lost hope.



I needed more bed/rest time and left a dirty kitchen or bathroom for days on end...not that I couldn't do it, I just did not care. Often I meant to hire regular permanent help for housekeeping and financial affairs, but forgot the intention within hours/days. Because I looked "normal", no one imagined how I felt, even when I tried to explain.

Ex-pats here in Mexico are a social lot. Everyone goes out to eat, plays cards, goes to listen to live music, takes yoga classes, volunteers at school, takes mini trips. I felt myself withdraw. I was sure I had nothing to add to conversation, was irritated by loud noises and voices, and was unable to recognize people at times. I began to seek nature instead which, fortunately, surrounds me. Few people seek me out.

Of late I realized I just don't want to be alone all the time. I learned how important it is to have frequent contact with people, be it by Skype or phone or email or in person. I am blessed to have my good friends at Dementia Alliance International, with whom I share warmth, humour, and I know, without asking, that they know what I'm talking about. I pick up Kate's book, watch Susan's film clip, see Mick's incredible courage and determination, and read Jeanne's wonderful emails... all letting me know I am not alone. Hiring help is just logistics, the other is love.

■ Research update

Effectiveness of persistent anti-dementia medication usage in dementia

Caryn Glosch, PhD, Assistant Professor, Director of Education and Patient/Family Services, Department of Neurology at Baylor College of Medicine



There has been ongoing debate about the value of anti-dementia drugs and how they should be used. Many questions plague people with dementia, their family members, and even their physicians. The most common

questions include: Do the current therapies do anything to slow the progression of Alzheimer's disease? Do they eventually stop working? How long should they be taken? What happens if they are stopped?

Before delving into the evidence to answer these questions, we need to address a couple of issues about the available data. First, we need to clearly define what counts as a “clinically meaningful benefit” in a progressive neurodegenerative disease, like Alzheimer's disease. Our ultimate goal, of course, is to cure the disease or get people back to baseline cognitively. Does that mean that those are the only “clinically meaningful benefits” or might slowing the clinical progression of the disease and preserving functional abilities also be “clinically meaningful benefits”? The latter is often of great benefit to the people with dementia and their family members. By including preserving cognition and functional abilities in the definition of clinically meaningful benefits, we provide greater opportunities for these treatments to demonstrate their value. Second, while randomized, placebo-controlled trials (RCTs) provide the most compelling evidence for the effectiveness of a given therapy, the lack of evidence from such RCTs for long-term use of Alzheimer's therapies should not be confused with evidence of a lack of effectiveness. There are numerous well-designed naturalistic studies that have provided crucial data when RCTs would be unfeasible due to prohibitive cost, high dropout rates, and the need for longer data collection times. Naturalistic studies provide the opportunity to examine the use of Alzheimer's drugs for far longer than would be ethical in RCTs, as withholding an effective medication for extended periods of time would be unethical (Atri et al, 2012; Rountree et al., 2013).

With this information in mind, let us examine the common questions about anti-dementia therapies.

Do the treatments do anything to slow the progression of Alzheimer's and do they eventually stop working?

While these medications probably do not modify the underlying pathology of the disease (Sabbagh et al., 2006), there is mounting evidence that persistent use of anti-dementia medications, especially combining an acetylcholinesterase inhibitor with memantine, is associated with slower decline in cognition and functional abilities (Rountree et al., 2009; Atri et al., 2008; Howard et al., 2012). In addition, people taking anti-dementia medications are significantly less likely to be placed in a nursing home (Lopez et al., 2009). These and other studies, which followed people usually for 6 months to 5 years (with some longitudinal, prospective studies having follow up for over a decade), suggest that not only do these medications not stop working, the benefits of treatment continue throughout the disease course (Atri et al., 2008; Zhu et al., 2013).

What happens if the medications are stopped? What happens if they are later restarted?

Research evidence demonstrates significant cognitive and functional declines following discontinuation of the medications (Doody et al., 2006). In the DOMINO-AD study in the UK, they found that people who stopped taking Alzheimer's disease medications for longer than 3 weeks showed significant declines in cognition and functioning (Howard et al., 2012). More troubling is the evidence that even after restarting the medications, they did not regain their former level of cognition or functioning (Crome et al., 2006; Doody et al., 2006).

Given the mounting evidence that these medications slow progression, preserve aspects of cognition and functioning, and continue working throughout the disease course, people should be diagnosed and treated early for AD and remain on treatment for as long as possible.

■ News

Dementia Friendly Communities reports launched at 2016 conference

New reports, 'Dementia Friendly Communities: Key Principles' and 'Global Developments' were released at the ADI conference in April. The reports contain details of the implementation of dementia friendly communities worldwide to date and the key principles that should underpin them.



The reports highlight the message that dementia should be everybody's business, detailing more than 100 dementia friendly initiatives from 23 countries.

ADI Chair Glenn Rees said that the reports explain the concept of what a dementia friendly community is, the benefits and the resources available to make a community more dementia friendly. "At one level the concept of dementia friendly is simple - to work for the common goal of a better life for people with dementia and their families. But it is much more than this. The framework of dementia friendly has the power to change the way we think about living with dementia."

ADI is encouraging members and others who run dementia friendly initiatives to submit details of their work through a new section on the ADI website at www.alz.co.uk/DFC. The reports, along with useful resources and case studies are also available there.

World Young Leaders in Dementia meet at ADI Conference

World Young Leaders in Dementia (WYLD) reflected on positive discussions and the importance of 'bridging the gap' in dementia research, inclusion and thinking, at this year's 31st International Conference of ADI in Budapest, Hungary.

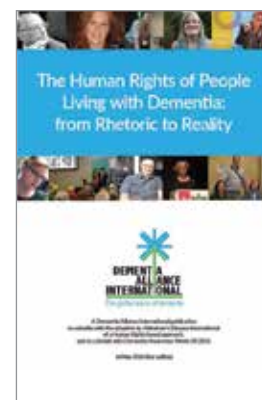


Marc, Kate and Mike meet with the young leaders in Budapest

A meeting of the group was held with Marc Wortmann, Executive Director of ADI, Kate Swaffer, Chair and CEO of Dementia Alliance International and Mike Splaine, ADI Policy Adviser, and looked at ways in which the group could engage with new approaches in research, strategies and policies to include younger people in dementia friendly initiatives. During the conference, the group conducted a survey resulting in positive support for a universal dementia friendly symbol to be adopted worldwide. We are now excited to invite the World Young Leaders to further discussion at our next conference in Japan in April 2017.

Human rights of people living with dementia

Dementia Alliance International has launched a new booklet, *The Human Rights of People Living with Dementia: from Rhetoric to Reality*. Chair, CEO and Co-Founder of DAI Kate Swaffer said the booklet would provide an important source of information for people with dementia and a crucial tool for addressing national and global policy that affects them - adhering to the motto: **Nothing about us, without us.**



The publication followed demands at the first World Health Organisation Ministerial Conference on Dementia in 2015, that access to the United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD) must explicitly guarantee the rights of people with dementia. ADI has since agreed to adopt a rights-based approach alongside Dementia Alliance International and is encouraging members to help actively incorporate this into global action.

You can download *The Human Rights of People Living with Dementia: from Rhetoric to Reality* from www.infodai.org/media-release-may-2016