The Executive Board of the World Health Organization (WHO) has recommended that the draft *Global Plan on the Public Health Response to Dementia 2017-2025* be put before all WHO Member States at the 70th World Health Assembly in May.

The decision was made after a statement was delivered by ADI at the 140th session of the WHO Executive Board in January.

Area one of the plan supports the urgent message that governments must develop national plans to address the impact of dementia in their communities.

The meeting follows the publication of a first public draft of the plan in December 2016, containing seven areas for action on dementia awareness, risk reduction, diagnosis, care and treatment, support for care partners and research.

A new area of the ADI website has been developed including the progress of the plan to date and answers to common questions.

Visit the global plan section at: www.alz.co.uk/dementia-plans/global-plan

34 members of the Executive Board supported the draft global plan in January 2017
Editorial
Marc Wortmann, Executive Director

As I write, there are less than 8 weeks until the 32nd International Conference of ADI in Kyoto and I am pleased that more than 2,000 people from many countries have already registered to participate at this important meeting of the world’s experts on dementia science, care and policy. The conference is likely to be among our biggest, and there is huge excitement that it will be followed in May by a vote on the adoption of a global plan on dementia by the World Health Assembly.

ADI and our members will continue to be essential as a vehicle for the necessary change to meet the targets of this plan by 2025, and are ready in 2017 to ensure that the momentum for improving dementia awareness, diagnosis, care and knowledge in partnership with governments and people living with dementia is long lasting.

For me personally, this is a result of a very long journey to convince WHO of the importance of a dementia policy, especially for the countries that are less resourced and need the support of WHO, and I am very glad it is now happening!

Area two of the plan is dementia awareness, and as part of this goal we welcome a greater involvement of stakeholders in government and in parliaments around the world in this year’s World Alzheimer’s Month campaign. Materials are already being developed highlighting a message of early detection and diagnosis, and a set of messages will be shared throughout the month under the ongoing theme of ‘Remember me’.

The conference will not only be an opportunity to progress these plans and others with our members in over 80 countries, but we are hopeful that the annual ADI Council meeting will present the opportunity to welcome new members to the ADI family that will aid and progress our vision for 2017 and beyond.

I look forward to meeting many of you in Kyoto where we will unite almost as a family and support and encourage each other with presentations, ideas and friendship. If you have not yet registered for the conference, I encourage you to do so now, by visiting the conference website at: www.adi2017.org
Meetings Roundup

10th Panhellenic Conference on Alzheimer’s Disease and Related Disorders (PICAD) and 2nd Mediterranean Conference Neurodegenerative Diseases (MeCoND)

Marc Wortmann, executive director and Anastasia Psoma, fundraising and membership manager, were invited to attend the 10th Panhellenic Conference on Alzheimer’s Disease and Related Disorders and the 2nd Mediterranean Conference on Neurodegenerative Diseases, which took place during February in Thessaloniki, Greece.

Alzheimer Hellas, in cooperation with the Panhellenic Institute of Neurodegenerative Diseases, organised the multidisciplinary conference which has informed and educated health professionals and care partners in Greece for over sixteen years. Marc presented at the opening ceremony of the conference, providing an overview of global dementia policies. This was the first occasion to report on the Global Action Plan on Dementia that is now proposed by the World Health Organization. It clearly marks Alzheimer’s and dementia as a global health priority.

Anastasia said, “I really enjoyed attending the conference. I had the chance to meet with many members of the federation in Greece to discuss new projects and fundraising issues with them as well as getting to know the new developments in the country following the launch of the Greek National Dementia Plan in 2016”.

Prof Magda Tsolaki, chair of the organizing committee, said “It was another very good opportunity for health professionals, patients, caregivers and stakeholders, to meet each other, change new experiences, new knowledge and future directions. More than 600 participants joined their efforts in order to improve the quality of life of Greek, Cypriot and rest Mediterranean patients and their caregivers.”

Community Based Rehabilitation Meeting in Geneva

Marc Wortmann, executive director of ADI and Kate Swaffer, Chair, CEO and Co-Founder of Dementia Alliance International, attended the meeting of the WHO this month, ‘Rehabilitation 2030: A call for action’, where they spoke of the importance of rehabilitation to those living with dementia, including its greater inclusion in the proposed global plan on dementia.

Rehabilitation is an important area of work for many diseases, and has a key role to play in achieving better outcomes for other health interventions such as surgery and hospital care. Despite this, it is largely unmet in global health planning and is widely under recognised as a vital area for the support of the elderly, and those living with dementia. As people living with dementia are increasingly being diagnosed earlier, and the global population is ageing faster, the missing ‘gap’ for rehabilitation has grown significantly.

The meeting included discussion on the strategic direction for coordinated action and establishing joint commitments to raise the profile of rehabilitation as a health strategy relevant to the whole population, as part of a continuum of care that includes prevention, treatment and palliative care.

Kate Swaffer said, “As the research and clinical dementia community forges ahead with diagnosing people with dementia in a more timely fashion, hopefully we will all get used to people with dementia functioning at much higher levels, for far longer than was once the case.”

Marc Wortmann said, “The disability community still has to get used to the idea that dementia is a serious disability, and that with the right approach it is possible to live well and independently with dementia.”

Find out more at: www.who.int/disabilities/care/rehab-2030
**TURKEY**

**Volunteers raise awareness at Istanbul Marathon**

Turkish Alzheimer Society joined 90 elite athletes from around the world to take part in the 38th Vodafone Istanbul Marathon on 13 November, raising greater awareness of their project named “Would you like to hold the hands of 500 Alzheimer patients?”

The project provides financial resources for a home care nurse service for bedridden individuals with Alzheimer’s disease. 185 volunteers ran on behalf of the Association as part of the Adım Adım platform that has raised more than 20 million Turkish lira (US$5 million) for NGOs across the region. Volunteers wore Alzheimer t-shirts, waved Alzheimer flags and shared the experience with supporters who donated to the project.

The Marathon on November 13th included participants from around the world, including professionals from Turkey, Belarus, Eritrea, Ethiopia, South Africa, Kenya, Russia and Ukraine. Adım Adım (Step by Step in Turkish), is a platform for creating awareness and resources through charity runs in Turkey and in 2016 charity runners for 29 NGO’s raised money and gave hope to 42,600 lives, 75% more than the previous year.

Dementia is estimated to affect more than 600,000 people in Turkey. Füsun Kocaman, executive director of Turkish Alzheimer Society, said, ‘In 2016 Adım Adım organization expanded number of NGOs taking part from 8 to 29 so we joined the platform. We are quite satisfied with both the amount of money we raised and the cooperative spirit we built. We are already practicing for the next marathon in Antalya on March 5, 2017.’

Visit the Turkish Alzheimer Society website at www.alzheimerdernegi.org.tr

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**INDIA**

**Encouraging young people to express their understanding of dementia**

Alzheimer’s and Related Disorders Society of India - Kolkata Chapter is encouraging young people to express their thoughts and feelings on dementia, through the “Smriti Sudhay” (“Where Memories Beckon”) project.

The project has received more than 209 poems, articles, stories, pictures and engagements since it started in 2008 and aims to support greater awareness and understanding of dementia among the younger generation.

The poem opposite was submitted by ten year old Iona Mandal in December 2016. Iona has won several awards for her writing from the age of just eight years old, after her parents moved to the UK from Kolkata, India.

You can find out more about ‘Smriti Sudhay, a project of ARDSI Kolkata chapter to involve young people to experience dementia’ on the chapter’s website at: www.ardsikolkata.org
INDIA

(continued)

My mind plays vagaries at time weaving remembrances and forgetting from anecdotes in this journey of life. In the interplay of light and shadow much is conquered yet, a lot remains to be regained as much is lost in the futile attempt to recovery over the sands of time and space.

So the past ridicules overlapping the present which ceases to manifest in the cage of the mind where jigsaws fail fitting for picture perfection As little niches await only to be filled perhaps, some day with memories of the mind crowded with voices, characters, plots and stories incidents and situations some deliberate and conditional often welcomed and desired while cruel comedies demand extinction for the bitterness they leave in the nooks of the mind.

There remains hope that some day the frivolities of the mind will but cease to reign as also the perennial bittersweet combat of the heart and the head where today’s object of desire is loathed the very next minute wiped, dusted and retrieved only to be lost again for the key to remembering is misplaced every now and then and never destined forever.

Iona Mandal

FINLAND

Alzheimer Society of Finland’s guide to working life for people living with memory disease

The Alzheimer Society of Finland (Muistiliitto) is encouraging employers, people living with memory disease and their families to study the possibilities of combining younger-onset memory disease and working life.

The brochure provides an essential resource for people living with memory disease and their employers, families and health professionals on a number of topics including continuing work, supporting employees and retiring with dignity.

The brochure is based on a small scale study conducted by the Society in 2015 on the attitudes and practices of neurologists and occupational health practitioners in Finland.

Memory disease, including Alzheimer’s disease, is estimated to affect up to 10 000 people of working age in Finland. Due to improved knowledge and diagnostic methods, more people are being diagnosed with the condition earlier, meaning that many individuals are able to continue working.

The brochure expands on a number of success stories featuring ordinary individuals who have continued to work in a supportive environment:

“The diagnosis was a great shock to both Aino and the whole work community, but it was a common decision that she should continue working. Our team felt that Aino’s input was still needed. Besides, we knew that she could continue working.

Her work day and week were shortened, her workstation remained the same and she was given tasks where the same routines were repeated and strengthened. We wanted to keep things as familiar and similar as possible.”

The brochure is available in English on the Alzheimer Society of Finland website at: www.muistiliitto.fi/en/memory-diseases/memory-disease-and-work-life/
How associations help

Support groups for care partners

The association in El Salvador hold regular support groups for care partners of people living with dementia, including Victor Manuel Quintanilla. The association also provides advice for people living with dementia, their care partners and others while raising awareness of dementia.

The association continues to hold monthly public discussions and, in January, Dr Velásquez Portillo started the year with a presentation on the myths of old age, and common misconceptions about dementia. Nurse Rosy Portillo followed the presentation by outlining the risk factors for dementia, and the meeting was concluded by a discussion on supporting the important people in our lives.

It is estimated that over 1.5 million people are living with dementia in central Latin America and the region is expected to see the greatest increases of people living with dementia of any region between 2015 and 2030.

By raising awareness of the symptoms of dementia, and the support that is available, the association plays an important role in increasing the support for those affected and tackling the stigma surrounds the condition.

You can contact Asociacion de Familiares Alzheimer de El Salvador at: alzheimerelsalvador21@gmail.com

Victor Manuel Quintanilla sought support from Asociacion de Familiares Alzheimer de El Salvador after his wife Maria was diagnosed with Alzheimer’s Disease in 2013. Alzheimer’s Disease is the most common form of dementia, accounting for 50-60% of all cases.

I have been married to my wife for 42 years. We were both born in El Barrio la Vega de San Salvador. Before the diagnosis, she was an employee of Philips El Salvador, balancing the many roles of Account Manager, wife, mother and the administrator of our home.

In 2013, she was diagnosed with Alzheimer’s Disease at the age of 75. My wife started to walk back and forth continuously, couldn’t sleep and found it difficult to express herself. The doctor said that we should prepare ourselves, as there is no cure for the condition.

For me, receiving this diagnosis was traumatic. I started to lose weight and was afraid. I contacted the Association of Relatives of Alzheimer’s of El Salvador and have been attending support groups arranged by the association every month since. The groups help me manage my feelings of fear, hopelessness and frustration with others who are also affected by the condition.

“I contacted the Association of Relatives of Alzheimer’s of El Salvador and have been attending support groups arranged by the association every month since.”

Thanks to the collaboration of my son Manolo, a friend and the Association, I continue to care for my wife with the patience and compassion that is needed.

I enjoy her company every time we go out, I always try to understand what she wants to tell me and involve her in activities so that she can interact with other people for as long as possible.

Alzheimer’s may steal your memory, but not your heart.
**Dementia Alliance International**

**Human Rights and Disability Rights news**

*Kate Swaffer, Chair, CEO & Co-Founder of Dementia Alliance International*

DAI’s January Webinar, ‘But you don’t look like you have dementia!’ was held in an attempt to expose how commonly this comment occurs, and how hurtful it is to people with dementia and their families.

These people are the ones who have sat in doctors’ rooms and been told they have a dementia of this or that type, or that their family member has it, and to get their end of life affairs in order and get acquainted with aged care services (often now referred to as Prescribed Disengagement®).

Their families have been sitting alongside them, trying to hold it all together, and pick up the pieces falling around them. This phrase is said all too often to people with dementia, especially those who are publicly appearing to live too well, whether they have become public advocates, or are simply living well in their local communities.

Judy Galvin from Australia has been living beyond a diagnosis of dementia, in her own home, for over ten years. She said of her experience of being accused of not having dementia:

“A ‘close friend’ challenged me recently when I explained that I just could not travel overseas, with the words ‘Anyway, you don’t have Alzheimer’s’. Each time I tried to respond, they kept hammering at me, repeating ‘You do not. You do not!’ Then, with a voice of ultimate authority ‘Anyway, others agree with me!’ - implying that friends we have in common see me to be a fake, a liar.

I felt terribly assaulted, as though I’d been stabbed, again and again – and by one of my closest friends? I was in shock, asking myself – Why would anyone ever do this to themselves. A life sentence! Losing so much of one’s quality of life – one’s mind? All the books you can no longer read, and so much more, and still trying to be “normal”. It was, and still is, devastating to feel betrayed, by someone so close to you.”

This habit, based on myths and preconceptions that everyone with dementia must look and act as though they are already in the late stage of the disease, needs to stop. It could also be seen as a disability hate crime.

There are many people who have been medically diagnosed with dementia now in the public eye, as speakers, authors and advocates, who may not look like they have dementia. In reality, not all the doctors around the world can be wrong. To assume otherwise is offensive; to the person diagnosed, to their families and to their medical doctors. It is harmful, hurtful and wrong for anyone without dementia to accuse someone living with this chronic progressive terminal illness, that, when diagnosed early enough, may have mostly invisible disabilities. Read the full blog at: www.dementiaallianceinternational.org/dont-look-like-dementia/

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**Annual report 2016**

Dementia Alliance International (DAI) have released their first Annual Report, including details of the accomplishments of the global self-advocacy group of people living with dementia in the organisation’s third year.

Download the report at:

www.dementiaallianceinternational.org/about-dai/annual-reports/
Living with dementia

Living well with dementia

Jeanne Lee, Hawaii, Co-founder of Dementia Advocacy and Support Network International and Dementia Alliance International member

Deciding to put all money into the cure that is years away instead of taking care of us now. How many of us can afford to get to an International Conference which is all about us?

I am one of few individuals still fighting 21 years after diagnosis of dementia. I survived attempted suicide, 3 years of care for depression, and have written a very successful book, ‘Just Love Me. My Life Turned Upside-down by Alzheimer’s’. I have been a member of nine national and international Alzheimer’s groups, on the Boards of three of them and travelled the world on my soapbox.

Wake up world; all we want is respect.

I was asked by another person with dementia, “What would a day all about you be like?”

I just completed a six week vacation all about me. My family made it all possible and I truly wish all these special moments for every person who is touched by or living with dementia. I want to give a special ‘mahalo’ (thank you) to Vern, my partner in care and best friend for wanting me to have this treatment and love.

Copyright: Jeanne Lee 2016.
Originally published at: www.dementiaallianceinternational.org/living-well-dementia-jeanne-lee/

Online support groups

DAI members facilitate and provide online support groups for people with dementia in six countries through online video conferencing.

Online support groups are ideal for those who cannot drive to their local “in person” support group or who live in isolated areas with limited access to services.

Find out more at: www.dementiaallianceinternational.org/services/online-support-groups/
I am a carer to my mother who was diagnosed with Alzheimer’s disease more than eight years ago. I was living and studying in the UK at the time and had no plans to move back to my native Hungary.

I visited my mother every couple of months, so that I could monitor the progress of her condition. Her illness was noticeable only when she talked, as she often replaced words with others which we would not normally use in that context. I could also see that she faced difficulties with numbers and handling money, and the countless notes in her flat as she wrote herself reminders.

What if she gets lost?

My mother was living on her own, but we would talk on Skype almost every day which gave me a peace of mind. We were not ashamed of her illness and talked to our friends and relatives about it, hoping that some of them could help support her. This did not happen and I was increasingly worried. “What if she gets lost?” I asked myself again and again. I felt that it was necessary to relocate to her in 2013. All I wanted to do was to keep my mum happy and active as long as possible, both mentally and physically.

There are almost 80,000 people in our town, Tatabanya, but there is no day care centre here and the help available for people with dementia is very limited. I wanted to help ourselves and others in the same situation, so I set up an Alzheimer Café two years ago - an unknown concept here. The Alzheimer Café was well received, but it is still difficult to reach out to people with dementia and their care partners.

The stigma attached to dementia seems far greater in Hungary than in some other countries. As I talked to people about my mother’s illness and the challenges we faced, I discovered that many of them had never heard of dementia.

“There was no assistance to support me as a care partner.”

They did not know what to say when I told them that my mother cannot use a fork and knife any more and that I had to help her dress. When we were in need of help, most of our family and friends disappeared from our lives. The telephone hardly ever rang and nobody came to visit us except one or two good friends. I feel that people with dementia should not be forgotten.
I have been working actively with volunteers to create an Alzheimer Café network in Hungary, which could act as a base to build dementia-friendly communities in the future. Luckily, this network is growing. I was really impressed by the great number of people who offered their help and were keen to improve the lives of people living with dementia and their care partners. In spite of being a care partner myself, I was able to support this project for two years, but stopped temporarily last summer when my mother’s condition progressed. She needed help with feeding, broke her leg, and had to stay in bed for a couple of weeks. Most films I have seen about the subject focus on the late stages of the condition which, in my opinion, only strengthens the stigma surrounding dementia.

Caring for my mother on my own became increasingly difficult. I was busy all day every day and hardly had a chance to sleep. I had no other option but to find a nursing home for her where she would receive proper care. Our first choice did not work out, but the second care home, where she moved three months ago, seems to be good by Hungarian standards. In the beginning, I visited her every day despite the one and a half hour journey there, but could not cope as there was no assistance to support me as a care partner. I still see her every other day so we can spend some time together and have fun.

As a filmmaker, I thought I could help to change the public’s perception of dementia by making an international documentary film about people living with dementia. I approached ADI with this idea shortly after my mother was diagnosed and asked for their help, so that I could start research. Since then, I have attended ADI conferences in Taipei and Budapest, and attended the Alzheimer Europe Conference in Copenhagen. The knowledge I have gained through these experiences has helped my work in Hungary, but has also contributed to the research for my film.

Most films I have seen about the subject focus on the late stages of the condition which, in my opinion, strengthens the stigma surrounding dementia. I would like to see more examples of individuals which prove that people with dementia can continue to lead happy and productive lives for a long time, if there is an early diagnosis, and, above all, if those around them understand how to provide support.

My research for the film entitled *Memory Trail* has slowed down over the past three years. However, I was able to travel last year to Wales, Scotland, Ireland and the Netherlands to meet others who are living with dementia. In 2017, I am aiming to continue the project with the support of a number of national Alzheimer’s organisations.

Connect with *Memory Trail* at http://blog.memorytrailfilm.com
Research update

Predicting Alzheimer’s disease dementia: It takes two to tango

Pedro Rosa-Neto, Serge Gauthier and Tharick A. Pascoal, Department of Neurology & Neurosurgery and Psychiatry, McGill University, Montreal, Canada

Biomarkers derived from brain MRI (Magnetic Resonance Imaging) and PET (Photon-Emission Tomography) imaging as well as Cerebral Spinal Fluid (CSF) measurements have become increasingly important in dementia research. During the last decade, large biomarker-based observational studies such as the Alzheimer’s Disease Neuroimaging Initiative (ADNI) have played a crucial role in measuring the progression of Alzheimer disease during clinical trials.

More specifically, biomarkers are capable of measuring the changes in the brain that happen in Alzheimer’s – the accumulation of amyloid, changes to the tau protein and progressive neurodegeneration. Biomarkers are playing a key role in the research criteria for the earlier and more accurate diagnosis of Alzheimer’s disease (Jack et al., 2011*, 2016).

In clinical trials, biomarkers provide unprecedented means to select the best study populations. They can also be used to see if the experimental treatment (usually a medication) reaches the desired therapeutic target. They are crucial to monitor safety of the new treatments.

Unfortunately, a single biomarker can’t tell us who will eventually develop dementia with certainty. However, an emerging hypothesis proposes that the co-existence between biomarkers rather than their single and independent effect can better predict the progression to dementia (Pascoal et al., 2016). This framework is based on initial observations in animal models (Ittner and Gotz, 2011) and in cognitively healthy people showing that the harmful effect of amyloid on the disease progression of dementia is changed by the abnormal levels of tau protein (Desikan et al., 2011, Fortea et al., 2014).

For example, Pascoal et al showed that brain metabolic decline, measured using PET-FDG imaging, in individuals showing no symptoms of dementia is driven by the combined effects of amyloid and abnormal tau protein in particular regions of the brain (the temporal and the cingulate cortices). A subsequent study revealed similar associations between amyloid and abnormal levels of tau protein as the driving force of clinical progression from Mild Cognitive Impairment to dementia, due to the development of Alzheimer’s disease in the inferior parietal and temporal lateral neocortex (Pascoal et al., 2016).

This emerging concept suggests that the coming together of multiple disease processes in certain vulnerable brain regions may constitute the driving force behind progression to Alzheimer’s disease symptoms. The presence of such a relationship between the two proteins would suggest that the effect of amyloid beta and tau protein on the progression of Alzheimer’s disease taken together is greater than the sum of their separate effects.

From a treatment perspective, this synergy of amyloid and tau pathology suggests that effectively treating one of the two components may be sufficient to slow down disease progression.


New website pages on global plan

A new section of the ADI website has been created that includes updates on the development of the World Health Organisation (WHO) Global Plan on the Public Health Response to Dementia 2017-2025 and answers to frequently asked questions such as “What is the global plan on dementia?” and “What can my government do to support people living with dementia?”

The draft global plan on dementia has been progressed for likely adoption at the 70th World Health Assembly in May 2017 after members of the WHO Executive Board positively supported targets of the plan for dementia awareness, risk reduction, diagnosis, care and treatment, support for care partners and research in January.

The new section accompanies existing pages on the development of national or state plans on dementia that have been implemented in 29 countries since 2005.

ADI are urging governments around the world to act now to prepare to meet the targets of the plan by 2025, including establishing national plans to tackle the unique experience of dementia in each country. A set of ADI infographics containing this message can be downloaded and shared from our ‘get involved’ page.

New sections of the website on clinical trials and dementia friendly communities were added in 2016.

Find out more: www.alz.co.uk/dementia-plans/global-plan

New World Alzheimer’s Month materials developed in 2017

ADI is preparing for World Alzheimer’s Month in September, including developing brand new materials for this year’s campaign using the theme of ‘Remember me’.

The theme will be accompanied in 2017 with a focus on early detection and diagnosis of dementia, and will include a series of social media banners developed for a range of key messages and case studies from people living with dementia, their care partners, health professionals and others.

ADI is continuing to work closely with members, Dementia Alliance International (DAI) and others to develop additional ways to support awareness during the month, including launching a brand new World Alzheimer’s Month website later this year.

A campaign poster, World Alzheimer’s Month bulletin and 10 warning signs graphic will be available for the campaign in English and Spanish during March, and can be requested alongside campaign toolkits for global non-profit and corporate organisations by contacting info@alz.co.uk.