



**Alzheimer's Disease
International**

The global voice on dementia

30 YEARS

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Global Perspective

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

World Alzheimer Report 2015

- 46.8 million** people living with dementia in 2015
- 74.7 million** people living with dementia by 2030
- 131.5 million** people living with dementia by 2050
- 9.9 million** new cases of dementia each year
- US\$818 billion** current economic cost of dementia worldwide
- US\$1 trillion** cost of dementia worldwide by 2018

On 25 August, ADI launched the *World Alzheimer Report 2015: The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends*, the seventh in a series of reports providing the most up-to-date global data on dementia. The report was supported by Bupa and contains findings from the latest research from King's College London's Global Observatory for Ageing and Dementia Care.

The report, which was launched with a live online roundtable discussion, provides the latest estimates of the numbers of people currently living with dementia worldwide and future projections. The report also contains current economic estimates, a figure which has increased by 35% since the previous estimate made in the *World Alzheimer Report 2010*. **Continued on page 3**



Loss of a true advocate

On 25 July, Richard Taylor sadly passed away at his home after fourteen years living with a diagnosis of dementia and two years after receiving the news that he had oesophageal cancer.

Richard, a former psychology professor, first became involved with ADI in 2009 when he attended and spoke at the ADI International Conference in Singapore. Prior to this event, Richard had been known to many for his campaigning, articles, chat rooms and the launch of his first book, *Alzheimer's from the Inside Out*, in 2007. He also ran a popular website, www.richardtaylorphd.com, to support and showcase his efforts to ensure people with dementia were respected and supported.

Even greater involvement with ADI came in 2011 following the ADI International Conference in Canada where Richard presented the idea for the *I Can! I Will!*

ideas library. The plan came to fruition that same year when www.alz.co.uk/icanwill went online with a great deal of work from both Richard and Laura Bowley.

In April 2014, Richard travelled to Puerto Rico to speak at the ADI International Conference. During his presentation in Puerto Rico, Richard said on behalf of people with dementia. 'We were, are, and will be up to about two minutes after we draw our last breath whole human beings.' While this comment seems more poignant now than it may have done at the time, it could be said that Richard lives on through the work that he set in motion and the many people that he inspired.

As per Richard's wishes, the Richard Taylor PhD Memorial Fund has been established with a number of pictures of Richard with his family. To find out more visit <http://www.gofundme.com/2t2a9usqc>



Alzheimer's Disease International

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Send us your comments

If you have any comments about or items for the newsletter please contact the Secretariat. Articles for the next issue of *Global Perspective* to arrive by 30 October 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
Web: www.alz.co.uk

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■ Editorial: The next 12 months

Glenn Rees, Chairman



I hope you are as pleased as I am with the *World Alzheimer Report 2015*. It provides a wonderful basis for advocacy at the global and country level over the next 12 months.

It is estimated that there are 46.8 million people worldwide with dementia, a figure that will rise to 131.5 million by 2050.

By 2018 it is estimated that the global cost of dementia will be US \$1 trillion.

ADI has welcomed in the conclusions and recommendations of the report the need for the 'call for action' agreed at the first WHO Ministerial Conference to be translated into an operationalised 'Global Dementia Action Plan'. With that in mind ADI has proposed the elements of planning for dementia at the global and country level that has the objective of supporting the person to stay in the community for as long as possible.

The over-arching objectives of these elements (see insert on page 3) are to reduce stigma, improve access to services, increase investment in research and prioritise risk reduction for dementia. And, in working for these objectives, we have to ensure that people with dementia and their families are put at the centre of all policies in the pursuit of equitable access worldwide to comprehensive services for people with dementia.

ADI has also indicated it would support and advocate for a transfer of political leadership to the G20 group of nations, assuming continued commitment and engagement of the G7 nations to the cause. The G20 accounts for 72 per cent of the world's population of people with dementia and includes those rapidly developing middle income countries where population ageing will be occurring most rapidly, namely China, India, Indonesia, Brazil, Mexico and Turkey.

I should like to thank Professor Martin Prince and his colleagues and staff in the ADI office for the hard work that has resulted in this comprehensive piece of work and to acknowledge the support of Bupa that has made it possible.

■ Events

13 – 16 October 2015
International Psychogeriatric Association International Conference
Berlin, Germany
www.ipa-events.org/ipa-international-congress

15 – 17 October 2015
8th Iberoamerican Congress on Alzheimer's Disease
Rio de Janeiro, Brazil
www.aibbrasil2015.com.br

15 – 18 October 2015
9th International Congress on Vascular Dementia
Ljubljana, Slovenia
<http://icvd.kenes.com>

18 – 21 November 2015
17th Asia Pacific Regional Conference of Alzheimer's Disease International
Manila, Philippines
www.aprc2015-philippines.com

9 – 12 March 2016
14th International Athens/Springfield Symposium on Advances in Alzheimer Therapy (AAT)
Athens, Greece
www.ad-springfield.com

17 – 20 March 2016
10th World Congress on Controversies in Neurology (CONy)
Lisbon, Portugal
www.comtecmed.com/cony/2016

21 – 24 April 2016
31st International Conference of Alzheimer's Disease International
Budapest, Hungary
www.adi2016.org

24 – 28 July 2016
Alzheimer's Association International Conference (AAIC 2016)
Toronto, Canada
www.alz.org/aaic

■ Cover Story

World Alzheimer Report 2015

CONTINUED FROM COVER

As with all of the *World Alzheimer Reports*, ADI offers solutions to support policy makers in addressing the increasing impact of dementia. The conclusions in this report particularly target those countries in the G20 group of nations, encouraging them to support wider representation of countries and regions, such as low and middle income countries where the largest increase in numbers of people with dementia is set to take place.

A new website, www.worldalzreport2015.org, was also launched to support the findings of the report, featuring key figures, downloads and advice on how society can support people with dementia.

The full report can be found at www.alz.co.uk/worldreport2015

The *World Alzheimer Report 2015* suggests the following actions as vital in supporting people with dementia

- Awareness raising of dementia
- Creation of dementia friendly communities that reduce stigma associated with the disease
- Promotion of risk reduction measures
- Measures to improve diagnosis and reduce the average length of diagnosis
- Support for family carers including through information, social support, respite and counselling
- Access to long term community and residential dementia care services and to enhanced care for people dementia in hospitals
- A commitment to person centred care and to care that minimises the use of medical and physical restraint
- Workforce strategies including training
- The use of technology to assist the person with dementia in the home and to extend service reach in rural areas
- Recognition that people with dementia deserve good quality end-of-life care with respect to their dignity and personal wishes



Members' forum

JAPAN

Carers award to benefit Association

In the last issue of *Global Perspective* we shared the inspirational story of Keiko Matsushima who has cared for her husband Kenji for over 10 years since he received a diagnosis of Alzheimer's disease at the age of 56. Keiko chose to keep the diagnosis hidden for a number of years, before news of an Alzheimer's Association Japan (AAJ) campaign on the government's long term care insurance reform motivated her to speak out. Keiko was awarded the 2nd ADI-Home Instead Family Carer of the Year Award in April for her ongoing efforts to raise awareness.

While part of the prize enabled Keiko and Kenji to travel to Perth, Australia for the ADI conference this year, an additional US\$500 was presented to Keiko. In order to thank those at AAJ's Toyama branch, Keiko has decided to donate the prize money to them to support the group activity which she found so beneficial in finally making the choice to share her story. For more information about the work of AAJ visit www.alzheimer.or.jp

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



Kenji and Keiko Matsushima

Members' forum

INDIA

Kerala State Initiative on Dementia



The opening of the new care centre

To meet the growing needs and numbers of people with dementia and their carers in the state, the Government of Kerala, in partnership with Alzheimer's and Related Disorders Society of India (ARDSI), has developed the Kerala State Initiative on Dementia (KSID).

The KSID pilot project aims to achieve the following: increased dementia awareness within the community; high quality dementia care training for social and health care personnel; memory clinics in medical colleges; dementia day care and full-time care centres; a telephone helpline service; establishing protocols for diagnosis, treatment and care; and developing standard operating procedures for dementia care centres.

In the six months since the initiative was developed, information leaflets and posters, as well as a carers manual, have been produced and circulated widely using government resources. A dementia day care centre is in the process of being set up and ARDSI is playing a key part in the training of existing staff in dementia care, including the government's helpline staff, care centre staff and the general public. Expert opinion is currently being sought on the setting up of memory clinics and standard operating procedures for care centres before they are approved. In May 2015, a full time care centre for people with dementia was established on a Public Private Partnership model.

The success of KSID relies upon all health and social care systems working collaboratively, but funds have been allocated in the state budget for the project. It is a great achievement, and one which is comparable to others in much higher income countries. It is hoped that KSID can be up scaled to cover the whole state of Kerala and serve as a model for other Indian states.

For more information about this initiative contact rdc@ardsi.org

NORWAY

New dementia strategy

With the Norwegian government's current National Dementia Strategy ending this year, the Norwegian Health Association have been campaigning for continuation of their commitment to supporting people with dementia and their carers. On 18 June, the country's Ministry of Health cemented their commitment for a further five years by launching the draft *Dementia Strategy 2020*. The draft plan was open for public consultation until 1 September 2015 and the Norwegian Health Association organised conferences for people with dementia and their families along with volunteers and scientists to have input into the new document. The new draft strategy focuses heavily on integrating people with dementia and their carers into communities, and an abridged version is also available making the document more user-friendly for people with dementia.

For more information about the new plan visit www.alz.co.uk/plans/norway

AUSTRALIA

New government research commitment

In early August, the Australian government announced that they will invest AU\$35.6 million into six Dementia Research Team Grants as part of their ongoing commitment to support and promote research into care, treatment and risk reduction for dementia. One of these grants will be used to develop the largest clinical trial in the world for people aged 55-75, testing an online tool to help reduce the risk of dementia.

It was also announced that Alzheimer's Australia will establish and run Australia's National Institute for Dementia Research, which will focus on a quicker translation of evidence from paper to policy and practice, as well as aligning the work of the institute with research being undertaken internationally.

For more information about the work of Alzheimer's Australia visit www.fightdementia.org.au

■ Member profile

Zimbabwe Alzheimer's & Related Disorders Association

Every Friday morning a small group of extremely dedicated volunteers, from an amazing array of skill sets, meet to assist a rapidly growing group of, mostly, elderly people living with dementia and conduct a vibrant art therapy session.

The art work is then cleverly engineered into greetings cards which are sold at various outlets enabling the art class to become financially self-reliant and of course gives the patients a huge sense of achievement. This is just one of the many activities initiated by the Zimbabwe Alzheimer's and Related Disorders Association, known simply as Zarda.

Founded in 1998 by Sue Cox, Zarda grew rapidly in its influence and became a full ADI member in 2004. It is run by an Advisory Board of four from the legal, medical and business sectors and there is an Executive Committee of 9 volunteers. Zarda is entirely self-funding and is a small Association with barely 60 paid up members. Of course the vast majority of carers, people with dementia and their families who are assisted by Zarda have not, and probably never are going to, pay the nominal subscription asked of them. That is the reality in third world economies.

The main drive of Zarda is all about raising awareness of and trying to dispel the myths and stigma so often associated with dementia. Formal workshops, social gatherings, information booths and fun events are all, at various intervals, deployed in high density suburbs and shopping malls to try and impart a better understanding of the various disorders causing dementia. Activities are also spread far out into more rural areas where the subsistence farmers and their

kin historically associate dementia with witchcraft.

Grass roots education and training is provided to various communities. Zarda offers support and counselling to families and other 'carers of people with dementia. Primary carers meet monthly on an informal basis (meaning tea and scones!) to share experiences, problems and, with luck, some successes. These carers meetings also provide a short period of respite and a chance to socialise with like-minded people.

Sing-alongs, mini concerts, Tea Dances, Laughter Therapy, simple yoga and other exercises and various activities such as dominoes and simple board games are all used throughout the year as another means of relieving tedium in the lives of people with dementia and carers.

The annual Memory Walk is held to create awareness and to give members of the public an opportunity to meet Zarda members and the committee. Informative and interactive talks are given to schools, both senior and junior, Nurses, Doctors (a difficult bunch to convince!), church groups, Service Clubs and women's groups. These are either formally organised by Zarda or, increasingly, requested. Chat shows on national radio have also been organised with fantastic results.

Zarda also offers training for carers who started out as domestic employees only to find themselves confronted with a case of dementia in the workplace. The courses are generally in the vernacular with the objective to give an understanding of the disease and how to deal with problem areas that are likely to occur in the future. Essential practical lessons on dressing,



lifting, feeding and bathing are also included. A slightly different course is also offered to Care Home staff.

Zarda offers a 24 hour help-line run by committee members, publishes a monthly news-letter and prints information sheets and leaflets in the three main languages. There is a comprehensive website at www.zarda.org from which one can also easily access a vibrant Facebook community.

There are many challenges facing people with dementia and their carers in Zimbabwe and people are seldom brought to medical facilities for diagnosis. Lack of national resources is very evident whilst, for Zarda, the shortage of both a financial and manpower pool poses a huge stumbling block. In future they will be striving to partner more effectively with other age-related charities and the Government to improve facilities for people with dementia and their carers.

■ Dementia Alliance International

An extraordinary legacy

Kate Swaffer, co-chair, co-founder and editor, *Dementia Alliance International*



Picture by Michael Hagedorn

Richard (centre) with attendees at the breakfast meeting he hosted at ADI's International Conference in 2012

The last quarter for Dementia Alliance International (DAI) has been a busy one, with the finalising of a number of projects, and the beginning of many new ones. The members of DAI, and the whole dementia community have been deeply saddened by the passing of Dr Richard Taylor, an extraordinary human being, and powerful dementia advocate for the lived experience and for our basic rights. An online *Memorial Tribute to Richard Taylor* was held on 19/20 August as part of our *A Meeting of The Minds* Series, an event started by Richard, available now on the DAI YouTube channel for anyone who was unable to attend but still wishing to view it. Richard was key to the launching of DAI, and had been hosting meetings for people with dementia at the annual ADI Conferences for some years.

Mr Marc Wortmann reminded us that ADI Toronto was the first conference where Richard asked for a meeting with the ADI leadership and as the result of their full programme, ADI agreed on a breakfast meeting at 7am on the morning after the conference dinner with ADI leadership and staff and everyone with dementia who was present. To ADI's surprise 25 people turned up! This was followed by a series of meetings at further events, the last we had in Perth where we discussed the formal collaboration of ADI with DAI. The formation of DAI has been crucial to establish a formal relationship with what started as a very informal group.

The seed for DAI originally sown by Richard, and watered each year as the numbers of people with dementia speaking out increased, has come to fruition, and I believe he would be proud of our progress. Our future plans include producing formal publications by people with dementia, the first on Dementia Friendly Communities of which we will launch at ADI in Budapest next year. Other publications in progress include *Consumer Empowerment*, *Communicating with People with Dementia* and *I've Just Been Diagnosed with Dementia: What's Next?*

2015 definitely looks like becoming a landmark year for DAI and people living with dementia. It started with the WHO's first ever ministerial conference on dementia in Geneva. At the opening session, I included access to the UN Convention on the Rights of People with Disabilities (CRPD) as one of the demands of DAI. Later, Marc Wortmann received unanimous support for an ADI Nothing About Us Without Us resolution, which was later incorporated into the Concluding Call for Action by WHO Director-General, Dr Margaret Chan.

Since then, DAI and ADI have been working together to gain full access to the CRPD for the worldwide dementia community alongside the other international NGOs working for people with other disabilities. We are being assisted by Prof Peter Mittler from the UK, a leading intellect in this area, and who has been involved in research and advocacy for the CRPD but has now joined DAI following his own diagnosis of Alzheimer's. His 2012 article on CRPD for ADI can be found at <http://dcidj.org/article/view/141>

Although we have not used our legal right to use the CRPD, we now need the support of all ADI national societies to ensure that the voice of people living with dementia is heard loud and clear when decisions that affect us are being made nationally as well as globally. The CRPD also empowers us to hold our governments accountable for translating its Principles and Articles into reality in our own communities.

DAI looks forward to welcoming new members, and working with ADI and country Alzheimer organisations, to educate, raise awareness, and to ultimately improve the lives of people with dementia and our family carers.

Finally, the greatest tribute we can offer Dr Richard Taylor and his extraordinary legacy, is to teach and empower others with dementia to STAND UP AND SPEAK OUT!

Tributes to Richard Taylor, PhD

The members of Dementia Alliance International, colleagues and friends of Dr Richard Taylor shared their personal reflections at an online tribute (www.youtube.com/ameetingoftheminds). This was an opportunity to remember Richard amongst others who also loved him, and to express our personal condolences and deepest sympathy to his wife Linda and their family.

A hero is an ordinary individual who finds the strength to persevere and endure in spite of overwhelming obstacles (Christopher Reeves); Richard Taylor will continue to be one of my heroes. **Kate Swaffer**, Australia

As I often say, one door closes and one door opens, thank you Richard for helping to prise the door ajar, and then to help push it open wider for those of us with dementia.

Keith Oliver, UK

Altho' you, Richard, have never met me, your online friendship, encouragement, support and information, plus your awareness-raising in the community and amongst medics, have helped me and other people with dementia and carers to keep calm and carry on - even tentatively (or confidently) to take up the baton and run for a little way!

Freda Colley, UK



Picture by Michael Hagedorn

I read Richard's book Alzheimer's from the Inside Out soon after my diagnosis at a time when I read all the books available on the subject and his was the only one that inspired me. Most of the others were unutterably depressing beyond words. I was also inspired that he used his past skills to learn from his daily frustrations and communicate them in a way that was familiar in order to help and inspire others. I shall be ever grateful to him. **Dr Jennifer Bute**, FRCGP, UK

I met Richard through his book Alzheimer's from the Inside Out. We found a Mexican printer to publish his book in Spanish; I had the privilege to review the translation. I admire his concepts, wisdom and most of all his sense of humour. He was really someone very, very special. We all, with or without dementia, are going to miss him enormously, but he showed us the path and we will follow it. Peace to a very special soul! **Dr Lilia Mendoza**, Mexico

Just like Richard did, Dementia Alliance International wishes to see hundreds if not thousands of people with dementia take his place and all STAND UP AND SPEAK OUT! **Dementia Alliance International**

A tribute from ADI Chair, Glenn Rees

I find it remarkable that only a few voices and faces resonate in my mind after many conferences around the world and in Australia. Richard Taylor's voice was one such voice.

He conveyed not just passion – the essential element for an advocate – but intelligence and a melancholy that commanded attention and a response. The melancholy perhaps the result of being ahead of his times and impatience for what he rightly argued was a compelling case for justice.

I cannot claim unfortunately to know Richard the man or to know what he meant to his family and those close to him. But on the two occasions I met Richard – set aside the many emails! – I was left with the indelible impression of what he stood for and the power of his mind. Richard was what he preached – a great individual.

I shared a parallel session with Richard at the 2009 ADI Conference in Singapore on consumer involvement. I followed Richard which was not much fun and a daunting experience. My policy and bureaucratic insights were not much of a match for Richard's passion and intellect. I still have in my 2009 consumer focus folder the talk he gave together with his plenary presentation.

When I next met Richard in Puerto Rico with Members

of Dementia Alliance International it was his sense of melancholy that that was most forceful and enduring. A conviction that despite all his wonderful words and passion that nothing much had really changed or perhaps ever would.

I could only give Richard my different view which was that, as a result of his efforts and those of many others, social attitudes to dementia since the turn of the century had changed to being more inclusive albeit slowly. I said much the same in emails to Richard.

I gave my commitment as I have to Kate and others that as Chair of ADI I would do all I could to make ADI an inclusive organisation. I am personally delighted that ADI and DAI are partners and that there is a developing programme of activity, including DAI conferences, which might re-assure Richard we are on the right path. These are testimony to Richard's memory.

I repeat that pledge. Through DAI and country based groups of people with dementia ADI will work for a world where people with dementia, in the words of the Scottish Charter of Rights for People with Dementia and their Carers, are able to exercise their rights at every stage of the illness.

I extend my sympathies and those of the staff at ADI to Linda and her family and Richard's fellow advocates around the world that he helped inspire.

How associations help

Relief efforts in Nepal

In April, Nepal experienced the biggest earthquake in over 80 years with aftershocks that continued to devastate parts of the country. While staff at the Alzheimer's and Related Dementia Society Nepal (ARDSN) dealt with their own personal reactions, they recognised the role they could play in responding to the needs of those whose communities had been devastated.

On 15 May, ARDSN's executive committee held a meeting to plan for emergency relief. The main objective set at the meeting was to provide emergency support and to address psychological trauma by providing psychosocial counselling and relief to those affected by the earthquake. Their key target groups were older people and children, while supporting communities and individuals in general. More specifically they chose the people of Farsidol Village in Lalitpur district, those requiring psychological support, as well as general counselling services in Gorkha, Sindhupalchowk and Dolkha. Key activities chosen to support relief efforts were: helping to build temporary dwellings for those in Farsidol Village; public awareness raising of the need for psychosocial and dementia care and recognition through radio and print media; providing training in psychological first aid to be delivered at camps run in collaboration with Nepal Geriatric Society, Netra Jyoti Sangh (eye care coordinators) and National Senior Citizen Federation; recruiting volunteers within three village development committees, and awareness raising for journalists.

A field visit to Farsidol Village, in partnership with Nepalese Doctors Association UK, took place in May to assess the situation and needs of its residents. The village covers an area of more than 9 square kilometres with 91 households and a population of 416, including 84 children and 44 older people. During the earthquake 10 houses in the village were destroyed and 80% were made uninhabitable. Through discussions with local people, it was clear that



Children and teachers at a school in Farsidol Village after receiving their gift packs during an ARDSN visit with Nepal Doctors Association UK

relief efforts should be channelled towards food and drink supplies for the primary school children, improving access from the houses to the main road, and shelter, food and water supply for the whole population. Two rooms within the school are no longer safe to use and improvements also need to be made to the school's toilet and drinking water facilities. Repairs are also required to the community hall, which provides day care facilities for older people. Work has already begun in Farsidol Village and a local management team has been set up to oversee progress.



The earthquake devastated a number of communities in Kathmandu and the surrounding areas

An appeal was sent out to ADI member associations and contacts earlier this year to support ARDSN's relief efforts. At the time of going to print more than US\$16,000 had been raised. ADI and ARDSN wish to thank all of those who have donated to the cause.

So much to learn

Glenn Rees, ADI Chairman

In May, I was a guest speaker at the Alzheimer Scotland Conference in Glasgow to mark Dementia Awareness Week. I asked if they would arrange for me to talk to consumer groups and staff as I have long been an admirer of the way Alzheimer Scotland is inclusive of people with dementia through the Scottish Dementia Working Group and their strategic approach to policy making. I had a wonderful week.

A comprehensive plan is falling into place based on the human rights of people with dementia that is captured in *The Charter of Rights for People with Dementia and their Carers in Scotland*. This has been given expression in action that embraces a commitment to achieve the timely diagnosis of dementia and to provide a year's post diagnostic guarantee to coordinate and plan support that responds to the unique needs of the individual.

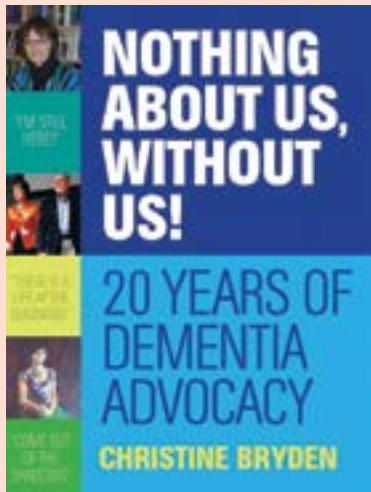
Action has been taken too, to enhance care for people with dementia in hospitals through the employment of dementia care nurses and the willing commitment of 500 hospital staff as dementia champions.

Living with dementia

Nothing About Us, Without Us!

Christine Bryden, Australia

Nothing About Us, Without Us! was the title of my talk to the 20th ADI conference in Kyoto in 2004, and is the title of my new book, to be published by Jessica Kingsley Publishers in September this year.



It is a collection of my talks since 2001, and includes several to ADI conferences, including the very first one in September 2001 at ADI Christchurch, called *Diagnosis, Drugs and Determination*. I remember the stunned reaction to that talk! By 2011 (ADI Toronto) I was able to reflect on a decade of positive change within ADI. The book includes a talk

in 2006 (ADI Berlin), where I speak of my candle sputtering out – but thankfully I have bounced back!

In 2000 a group of people with dementia formed the Dementia Advocacy and Support Network International (DASNI) and approached ADI in mid-2001. We felt that our exclusion from full and equal participation was unethical. Without our expertise in the lived experience of dementia, how can policies, programmes and services truly meet our needs?

People with dementia want to have the choice to participate in the international dementia movement. We can be

passionate advocates for a cure, and for support and treatment. Although only a few will want to get involved, we must be given the choice.

As I said so many years ago in Kyoto: 'In this relay race towards eliminating stigma, and towards self-determination, each one of us... is carrying a baton of change. But... we are declining daily. Not all of us in DASNI who picked up the baton and began the race in 2000 are still running. Together we can enhance... the services and support provided through the global Alzheimer's movement... and adopt the slogan "Nothing about us, without us!"'

I am thrilled to learn of the collaboration between ADI and Dementia Alliance International (www.dementiaallianceinternational.org), which has taken over the baton for change, working towards full inclusion and participation of people with dementia, the experts in the lived experience.



Christine (left) with Helga Rohra from Germany and Lynda Hogg from Scotland during the ADI Conference in Toronto in 2011

Picture by Irene Borins Ash

So much to learn Continued

The next step – maybe in October this year – is to produce a policy document on end of life care.

When you have a few hours do visit the Alzheimer's Scotland website at www.alzscot.org to learn about the Charter, the consumer groups and the policy captured in the five pillars and nine pillars documents.

Through the wonderful Dr Mayumi Hayashi in London I have also started to become more familiar with the fascinating developments in support and care in Japan through Long Term Care Insurance. There are the multi-functional community centres that provide 24 hour

access to health care and respite, dementia day centres, 35,000 day care centres (providing access to 1 in 3 eligible people) and dementia group homes. I have long believed that good respite care is critical to dementia support and Japan seems to be providing some of the answers.

I drew on some of what I have learnt recently in a talk I gave in Australia, *Dementia: The Global Scene and Lessons for Australia*, available at www.alz.co.uk/speeches. We all have an awful lot to learn from each other both in recognising the needs of countries that have very little to those who are at the cutting edge of systemic change in their health and care systems to tackle dementia.

■ Carer's story

A Carer's Plea *Ann Pascoe, Scotland*

In 2006, my husband Andrew was diagnosed with vascular dementia. I was told I had two choices: I could leave my husband or accept that my life was on hold.

The first was not an option. And the second one so upset me, it took a year to realise there was a third choice, which was that I had to take a different journey, one I'd not anticipated, but one that could nevertheless be fulfilling.

The provision of decent, proper care for people with dementia in Britain is sorely lacking. I know this from experience ... and ironically so too do the professionals: a recent survey of 1,000 doctors by the Alzheimer's Society found that three in five GPs think that people with dementia don't get enough support thanks to a lack of cooperation between the NHS and social care. 73% also think that people are left confused by the health and social care system as it exists right now. They are right.

We are lucky enough that I was able to become a carer for Andrew. Many people don't have that option. But even for family carers, there can be gaps. In Scotland, where I live, for example, the law states that both the person with dementia and the family carer can have access to a year's post-diagnostic support, which is supposed to set you on your dementia journey. But while in theory, this sounds great, the reality is that it is not working too well.

For a start, one is usually so traumatised during that first year, you can't even begin to think where to go or what to do. By the time you do need support, the one year is up.

Then there are those who have been diagnosed for more than a year – sometimes for even ten or fifteen years – who still do not have proper support. These are the families who fall through the cracks – and these are the families whose carers keep going until they hit a crisis or they themselves become ill. These are the carers who learn all the coping strategies, more often than not through trial and error, and encourage their loved ones to do what they can to keep their brains busy and their bodies active. The problem is, because we are then deemed to be “coping”, we are ‘thrown off’ the books.

But the diagnosis hasn't gone away. The carer is still caring, and the person with dementia is still trying to come to terms with this difficult life. Perhaps the worst thing, though, is that too many professionals still do not include the carer or the family in key decisions; they simply make whatever choice – about testing, care, the future – they believe is right, and the family has to live with it.



Ann with her husband Andrew

So what can be done to fix the system?

First, the time has come to declare dementia a long-term illness – in the same way that cancer or diabetes are – so that local district or practice nurses become regular points of contact. We talk about champions and support workers and goodness knows what else, but all we as dementia families want is to have one person who knows our story, can hold our hand and point us in relevant directions throughout our journey, so that we don't have to relive everything every time we see someone new.

Secondly, it is time to insist on a triangle of care involving the person with dementia, the carer and the professional. Any time any decision is made by any professional at all, the person with dementia and the primary carer should also be involved. After all, we are the ones living with the daily business of looking after our loved one - not just for an eight-hour shift, or even a 35-hour week, but for 168 hours every week, every month and every year.

What dementia families really want is simply to live an ordinary life, doing ordinary things. The more that people with dementia can be supported in socially inclusive communities, rather than being side-lined into dementia ghettos, the better it will be for all concerned.

The saddest thing for me, however, is that I'm no longer a wife: I'm a carer. I need support as much as my husband does. That also needs to be recognised. Classifying dementia as an illness, and organising a more joined-up system of care would be a good start.

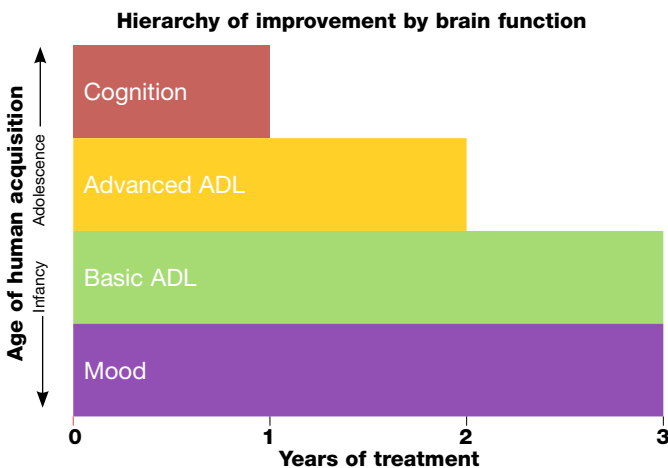
■ Research update

Benefits of long-term cognitive motor intervention last longest on basic daily life activities

- **Researchers compared effects of a three-year-long cognitive motor intervention for people with Alzheimer's with people who received usual care.**
- **Long term cognitive multicomponent intervention produces relevant improvement in daily life of patients.**

This first, long-term study on the impact of a multicomponent cognitive stimulation programme for people with Alzheimer's has shown that the benefits of this intervention last longest on the basic activities of daily living - those skills learned in the earliest years of life - and mood. The study results, which have just been published in the *Journal of Alzheimer's Disease* under the title *Cognitive-Motor Intervention in Alzheimer's Disease: Long-Term Results from the Maria Wolff Trial*, have many practical implications for Alzheimer's treatments.

The research team discovered that the impact of long-term multicomponent cognitive stimulation programmes is varied, depending on the brain functions.



The long-term effects of exposure to this kind of non-pharmacological therapy remained unknown until this publication. These treatments are usually provided by day care centres, memory units or nursing homes, services that people with Alzheimer's often use for a period of years.

In order to evaluate the outcomes of such long-term treatment, two groups of about 40 people each were compared over three years. One group received a cognitive motor intervention through sessions lasting about 3.5 hours twice weekly, whereas the other received usual care.

The intervention method called "Animus" returned several benefits after one year: participants had better cognitive performance, were more independent in daily



Ruben Muñiz



Javier Olazarán

activities, and showed both better mood and adapted behaviour. In addition to the latter, this group took fewer mood and behaviour drugs, as compared to people without the programme who were seen to exhibit more depressed moods, less adapted behaviour and took more psychotropic drugs. These improvements are clearly relevant, as they show that such a non-pharmacological therapy can improve people's quality of life while avoiding the risks of psychotropics.

A clear hierarchical response to therapy emerged from the data: improvement in cognition - understood as language, comprehension, thinking and orientation - maintained statistical significance for only one year. Instrumental Activities of Daily Living, such as use of money or preparing a meal, improved significantly for two years. The winning domains, those that showed significant improvement over three years were: a) Basic Activities of Daily Living like showering, dressing, toileting or eating; and b) Mood, showing those attending the sessions less depressed than those that received usual care.

Ruben Muñiz, Research Director at Maria Wolff Foundation, remarks: "It is as if those cerebral circuits wired during infancy (eating or toileting) responded longer to non-pharmacological treatment than those acquired later in adolescence (making meals or intellectual comprehension). Data show a temporary hierarchy of responsiveness to our therapy: the brain functions of latest acquisition in human development were the least responsive, while the functions acquired earliest were the most responsive".

Dr Barry Reisberg at New York University Langone Medical Center, adds: "Brain functions acquired during early human life withstand Alzheimer's neurodegenerative processes for a longer time than those acquired in later life, for example in adulthood, adolescence or later childhood. This process is called Retrogenesis, and has been described as part of the normal evolution of Alzheimer's disease". **Continued on page 12**

■ News

25 years of your GP

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

News from 2004: In our December 2004 issue, we marked 20 years since the founding of ADI as well as record-breaking involvement in both World Alzheimer's Month and ADI's 20th International Conference in Kyoto, Japan. The conference was attended by over 4000 delegates and marked a cultural turning point with Japanese people with dementia speaking out about their experiences for the first time.



To read this and other back issues of *Global Perspective* visit www.alz.co.uk/newsletter

In the next issue of *Global Perspective*

- A report on World Alzheimer's Month
- News from the Alzheimer Europe, Latin America and Asia Pacific regional conferences

Marking World Alzheimer's Month

September



World Alzheimer's Month

Remember Me



Join the campaign

World Alzheimer's Month has begun! To find out what events are taking place in your country this September or to add your event to the listing visit <http://worldalzmonth.org>

■ Research update CONTINUED FROM PAGE 11

The two study leaders, Ruben Muñiz and Javier Olazarán, point out the practical implications of this study: what, and in what way cognition is stimulated and maintained should be carefully revised, especially after mild dementia. The role of instrumental and basic functioning of daily living should be more specifically targeted from the time mild dementia is diagnosed, onwards. In addition, the emotional and physical well-being should be actively addressed at every stage of the disease.

Scientists at Maria Wolff Foundation stress that this study is the first of its kind in terms of length and quality. All study participants (control and treatment groups) were taking drugs called cholinesterase inhibitors. These drugs can slightly improve cognition in some patients. As the treatment group received cognitive-motor stimulation and the drug, the additive effect of the intervention could be measured.

Patients and their caregiving partners were consistently satisfied or very satisfied over the three-year period of attending the Maria Wolff day care centers in Madrid, where these treatments were provided. Dr Javier Olazarán, Scientific Director of the Foundation, said: "Participants enjoyed socialising and did not mind the effort of attending the sessions regularly. Their acceptance is important, as it does not only pay back for them in clinical terms, but because it gave caregivers twice weekly relief".