

September 2010 Volume 20 No.4

Global Perspective

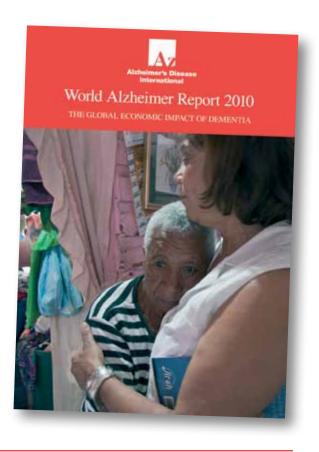
A newsletter for Alzheimer's Disease International, The International Federation of Alzheimer's Disease and Related Disorders Societies, Inc.

The global cost of dementia

On 21 September, ADI releases the World Alzheimer Report 2010, presenting the most comprehensive figures to date on the global economic impact of dementia.

The report, which builds on the findings of the World Alzheimer Report 2009, includes estimates of the worldwide cost of dementia and considers the direct medical costs, direct non-medical costs and costs of informal care. The report also contains policy recommendations and makes clear to key decision-makers worldwide that doing nothing is not an option.

A full report on the launch of the World Alzheimer Report 2010 across the world will appear in the next issue of Global Perspective. The report and an Executive Summary are available on the ADI website at www.alz.co.uk/worldreport



Do you have a psychosocial intervention?

For the third year running, ADI have teamed up with the Fondation Médéric Alzheimer to offer an award for the best evidence-based psychosocial intervention project and the most promising evidence-based psychosocial intervention.

The purpose of the award is to support and enhance the use of psychosocial interventions in improving the quality of life for people with dementia and their carers.

Submissions for the best evidence-based intervention



Winner of the 2010 award, Dr Amit Dias (second left), with his project team

category should already have been implemented and evaluated, and projects for the most promising award should show some positive outcomes with a need for further implementation.

Awards will be given for the winning project in each category. The prize for the best evidence-based psychosocial intervention award is €18,000 and for the most promising evidence-based psychosocial intervention €7,000 will be awarded. The awards will be presented during ADI's International Conference in Toronto. Canada in March 2011.

The deadline for applications is 31 October 2010. For more information and terms and conditions of entry please visit www.alz.co.uk/award



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 29 October 2010.

Secretariat

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Editorial



Marc Wortmann
Executive Director

This issue of Global Perspective contains some exciting updates on policy work in the Alzheimer's movement. The first objective of the ADI Strategic Plan 2010-2013, as approved by our members at the conference in Thessaloniki, states that 'ADI will continue to advocate for dementia to be a global health priority of the World Health Organization and a national priority in more countries'. Many Alzheimer associations are using the month of September and World Alzheimer's Day 2010 as an opportunity to advocate for this goal. In the USA, researchers are cycling from the West Coast to

the East Coast (finishing in Washington, D.C. on 21 September) to encourage their government to work on a national strategy. The Alzheimer's and Related Disorders Society of India has commissioned its own strategy as a call for action and many other associations are doing the same in their countries.

The time is better than ever for these appeals. It becomes more and more apparent what a burden Alzheimer's disease and other dementias are, not only on our families but also on our societies. ADI launches the World Alzheimer's Report 2010 on 21 September. The report contains new economic data and it is not a positive message. However, we hope it will support you in your work to emphasise the need for action everywhere: in your hometown, your province or state, your country, your region of the world, and globally. As our theme for World Alzheimer's Day 2010 states: 'It's time for action!' It is time indeed and I wish you all great success with your work!

Events

20th Alzheimer Europe Conference

Luxembourg

Email: info@alzheimer-europe.org

Web: www.alzheimer-europe.org/conferences

20 - 23 October 2010

Seventh International Congress on Vascular Dementia

Riga, Latvia

Tel: +41 22 908 0488 Fax: +41 22 906 9140 Email: vascular@kenes.com

Web: www2.kenes.com/Vascular/Pages/home.aspx

21 - 23 October 2010

IV Congreso Iberoamericano sobre la enfermedad de Alzheimer y IV Congreso Nacional de Alzheimer

Seville, Spain

Web: www.congresonacionaldealzheimer.org

22 - 24 October 2010

13th Asia-Pacific Regional Meeting of Alzheimer's Disease International

Kuala Lumpur, Malaysia Tel: +603 7956 2008 Fax: +603 7960 8482 Email: adfmsec@streamyx.com Web: www.alz2010.org

28 – 31 October 2010

The Fourth World Congress on Controversies in Neurology (CONy)

Barcelona, Spain
Tel: +972 3566 6166
Fax: +972 3566 6177
Email: cony@comtecmed.com
Web: comtecmed.com/cony/2010

3 – 5 November 2010

Third Conference on Clinical Trials on Alzheimer's disease (CTAD)

Toulouse, France Tel: +334 6710 9223 Email: ctad@ant-congress.com Web: www.ctad.fr

26 - 29 March 2011

26th Annual International Conference of Alzheimer's Disease International

Toronto, Canada Tel: +44 870 458 4171 Fax: +44 870 442 9940 Email: adi2011@mci-group.com Web: www.adi2011.org



The Changing Face of Dementia

Register online now for ADI's 26th International Conference in Toronto, Canada from 26-29 March 2011. Visit www.adi2011.org for more information.

3



A letter to my Mom

Siu Mei, Hong Kong, SAR China

Dear Mom,

Do you remember the day that our doctor informed us that you are affected by Alzheimer's disease? Both of us could not believe it and I asked many doctors many questions to reconfirm or even challenge the doctor's diagnosis. Time flies fast and it was already seven years ago.

It was 2003, when I made a phone call to you as I did on many other days; I was shocked to hear that it was a policeman who was at the other end of the phone. You got lost in the housing estate of our residence! Luckily, the security guard gave you a helping hand, but you totally forgot your own address. So he called the police for help. I realised that there were some problems with vou! At that moment, I really felt guilty. I should have paid more attention to you. Why didn't I realise that you might have been facing difficulties for quite a period of time?

In the early stage of the disease, you still tried your best to take care of yourself and prepare meals for my brother every day. As time passed by, your cognitive function and self-care abilities deteriorated progressively. Now, our roles have exchanged! It doesn't matter, let me look after you and prepare meals for you, although my cooking skills are not as good as yours.

In 2005, I resigned from my job and decided to start a new life with you. I asked you to live together with me so that I could take care of your daily living. Mom, thanks for your acceptance. You adapted well in my home, which was a new environment for you and might confuse you sometimes.

Every day we take a walk outside in daytime in order to maintain your muscle fitness and also to give you different stimuli around our living place. Sometimes, your active response to the surroundings is great fun to me. You



Siu Mei's mother with staff at the Hong Kong **Alzheimer's Disease Association's Centre**

chased the birds in the park. It's nice that you seem to become young again. But you forgot that you would fall over easily. While you chased and played with the birds, I needed to chase after nervously, afraid of your falling. Now, when we are at home, I try my best to schedule some meaningful activities, such as cognitive games in order to slow down your deterioration and that is my only wish now.

You may realise we have not gone out for dinner for quite a long time. It is because you are quite nervous in an unfamiliar environment after sunset. You may also wonder how come a travel-lover like me always stays at home in recent years. It is because I am afraid that others cannot take good care of you. I worry that you cannot get along with others. I will not sleep tight at night so as to keep an eye on you. There was a night in winter, while I was still awake; I realised that you had been in the toilet for a long while. I went to check and found that you had wet your pants and you stood there stiffly, looking so helpless. Thank God I did not sleep tight; otherwise you would definitely get a cold!

Mom, you are always a neat and candid person, even after you got the diagnosis of dementia. However, sometimes your sudden actions would scare us. We were once on the way home on a ferry, you saw a man whose tie was a bit lopsided, and you tried to help him to put it right. There was also once a passer-by's trousers touching the ground, you went over and told the man it wasn't clean. Although these actions were out of kindness, it was understandable that these people would feel awkward.

The most unforgettable incident must be when you got lost in Hong Kong Island! We usually passed the market when we went to Jean Wei Centre of Hong Kong Alzheimer's Disease Association. Sometimes, I would skip to buy something quickly and you were always waiting for me guietly at the entrance. It was a rainy day. Fearing that you might fall down on the slippery floor, I asked you to wait on the opposite side of the entrance, and reminded you not to walk away. However, when I went out of the market. I did not see you there. I was in an awful fluster and kept searching around, but I could not find you! Fortunately, a policeman found you and brought you back to me. They said you followed others to get on a mini bus. Luckily, the security guard got you, if not; I could not imagine the consequences. I can recall now how frightened and scared you were, it made my heart ache. I promise, I will never let you out of my sight!

I used to have many wishes, but I only have one now. I wish your cognition could be maintained. If it must be in regression, please take it slowly. This is my only wish! I will try my very best to take care of you. It's my way to love and care for you in return for your unconditional love to me as my Mom!

Love, Siu Mei



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

CHINA



Collecting Clinical Experiences, Caring for Patients

Huali Wang and Ivy Guan-Yu Lu

Since its founding in 2001,
Alzheimer's Disease Chinese (ADC)
has been contributing to service
for people with dementia and their
families. Many training programmes
have been conducted to improve
the quality of care for people with
dementia. Over 5,000 physicians
and caregivers have been trained
through experts' lectures, case
forums, public campaigns, and
caregiver support groups.

Recently, in collaboration with Lundbeck China Ltd., ADC initiated the Case Collection Program, aiming to promote the care of people with dementia through case experiences and raise physicians' awareness to play a role in the improvement of quality of life for people with dementia. This programme will contribute to increasing the responsibility of physicians to provide comprehensive care for people with dementia, in addition to prescribing medication. The programme will collect case reports nationwide, focusing on the case diagnosis and care, with particular attention to follow-up visits to observe the quality of life of the patients and their families. It is believed that the programme will build an interactive platform for physicians across the nation, and will contribute to clinical care and social support for people with dementia.



A collaboration between SNCF, the French train company, and France Television, in partnership with France Alzheimer and a number of other organisations, will see an Alzheimer Train tour the country from 7 to 21 September.

Train contre la maladie d'Alzheimer (Train against Alzheimer's disease) marks the 258th train exhibition and aims to inform and educate the general public and provide answers for those who may have questions about Alzheimer's disease.

The train will stop at 12 towns and cities around the country and will consist of 14 carriages, with eight devoted to the exhibition. The exhibition will explore all aspects of the disease with four main categories: understanding the disease, living with the disease, the involvement of carers and focus on research.

An allocated conference car will also be in use throughout the day with on-board events including a range of presentations and lectures given by experts and a daily screening of Des mots d'amour (Words of Love), a drama about accepting that you have dementia.

Details of France's national Alzheimer Plan 2008-2012 will also be made available to the public on the train, clearly outlining the 44 solutions contained within the Plan to improve the quality of life of people with dementia and their families and speed up research efforts.

To find out more about Le Train Alzheimer visit www.train-alzheimer.fr.

MEXICO



Honorary guest at the laying of the care centre's first stone

On 16 May, the first stone was laid in the construction of Federacion Mexicana de Alzheimer (FEDMA)'s day care centre for people with dementia in Reynosa.

The city's major, LIC Oscar Luebbert Gutierrez, attended the event, along with his wife, Esther Camargo de Luebbert, Director of Desarrollo Integral de la Familia (the Integral Programme of Families). Also in attendance were Daisy Acosta, Chairman of ADI, Nora Eneyda de la Garza, FEDMA's newly appointed President, and Eliud Robles Almaguer, President of the local Alzheimer's association.

The land on which the day care centre will be built was donated to the association in Reynosa by the City Council and will cover an area of 2,500 square feet. The centre will be the responsibility of the architect Pedro Ordoñez and Eliud Robles Almaguer, who explains, 'This is a place to care for the sick, sharing the responsibility of caring for them, along with their families.'

FEDMA wish to extend their thanks and congratulations to all who made this project possible.

NEW ZEALAND

Hats on for dementia

Supporters of the Alzheimer's Society South Canterbury, a member of Alzheimers New Zealand, took part in an innovative awareness and fundraising activity during March. Seventy-five men and women wore hats for three weeks to raise money through sponsorship and fundraising for people with dementia and their carers in the local community.

Sandy Landrebe, one of the participants said, '[My friend] rang me and asked me to be a part of it. I thought it would be fun and is something to do for Alzheimer's.'

A number of hats were donated to the cause and, in the final week of February, hat wearers met the event organisers to select their headwear for the occasion.

On the day of the meeting, Alzheimer's Society South Canterbury president Diane Nutsford said,



Some of the hat-wearers with the hats donated to the cause

'They've all said 'when can we start, do we have to wait until March 1?' Everybody who has been in to select a hat has been so positive, it's been absolutely nothing but giggles and laughs all afternoon. It's been fabulous.'

The fundraiser concluded with an event at Caroline Bay in Timaru under the theme *On the Bay in Days Gone*

By, featuring a barbershop chorus, country band, Highland dancing and bagpipes, a vintage car group and people in Edwardian costume.

The fundraiser made a total of NZ\$18,000 and the money raised will go towards a volunteer programme, with some volunteers already recruited amongst the hat wearers.

USA

New TrialMatch service available



During the Alzheimer's Association's International Conference on Alzheimer's Disease (AAICAD) in July, a new service was launched to allow people with dementia, carers, families and physicians across the USA to easily find clinical trials in their area.

Alzheimer's Association TrialMatch™ was developed in response to the problems faced by research facilities in recruiting and retaining participants. After funding, it is believed that finding volunteers is now the greatest obstacle to developing new treatments for dementia in the USA.

The process is broken down into four clearly defined steps.

Initially, the participant contacts the Alzheimer's Association either online or by telephone. Participants are asked to complete a short questionnaire, which pays particular attention to the person's diagnosis and current treatment. The Alzheimer's Association then compares the participant's criteria to the trials on their comprehensive database and contact the participant to inform them of the most suitable category of trials that match their criteria.

All trials considered for inclusion in the TrialMatch database must provide proof that an institutional review board has approved them and are also vetted by the Alzheimer's Association to ensure they are credible and safe for participants.

For more information, visit www.alz.org/trialmatch

BANGLADESH

Alzheimer Society of Bangladesh receives donation

The Alzheimer Society of Bangladesh (ASB) has received a generous donation of 25,000 Bangladesh Taka to support their ongoing work.

The donation was received from Mrs Refat Murshed, daughter of Mr Khaney Alam Khan, the former divisional commissioner in Dhaka who died in November 2009, following a prolonged illness with Alzheimer's disease.

Mr Khaney Alam Khan's story was told through the carer's story in the last issue of Global Perspective (June 2010).

ASB are very grateful for this kind donation and wish to thank Mrs Murshed for her support.

■ Advocacy Special

ADI at the World Health Assembly

In May 2010, representatives from ADI attended the annual meeting of the World Health Assembly, the decision-making body of the World Health Organization (WHO), held in Geneva, Switzerland, to further ADI's mission of encouraging the WHO to declare dementia a global health priority.

Yasmin Raashid, ADI Board member, Hussain Jafri, Secretary General of Alzheimer's Pakistan, and Marc Wortmann, Executive Director of ADI, attended the meeting, where they had the opportunity to speak to representatives from departments of health and of foreign affairs in the USA, Canada, UK, Netherlands, Switzerland, Japan, Norway and others.

During the event, two meetings took place between ADI and the WHO. The first with John Beard, Director of Ageing, and Tarun Dua, from the department of Mental Health, Neurological Disorders and Substance Abuse, and the second with Shekhar Saxena, the head of that department. During the first of these meetings the Global Alzheimer's Disease Charter was presented along with the special Charter edition of Global Perspective, a breakdown of the signatures for the accompanying petition by country and testimonials given by people who signed the petition. The number of signatures, 54.821, was considered very high for an international initiative and is a clear indication of how serious the problem is.



Hussain Jafri, Yasmin Raashid and Marc Wortmann presented the results of the Global Alzheimer's Disease Charter to WHO Director of Ageing, John Beard (second left)

Feedback from the meetings suggests that the WHO was pleased with the World Alzheimer Report 2009 and they have shown a keen interest in being involved in the launch of the World Alzheimer Report 2010 after receiving a number of enquiries from international press following the launch last year.

The ADI representatives were also informed that the continued pressure ADI and its member associations have placed on the WHO to recognise the importance of dementia has been influential. Dementia is now a priority in the Mental Health Global Action Plan (MhGAP), which will be implemented shortly in a group of lower and middle-income countries. The WHO are keen to prepare a press release for World Alzheimer's Day, using the Global Alzheimer's Disease Charter as a reference. They also suggested collaborating with ADI on a WHO report on dementia to be released in 2012, with the aim of encouraging a resolution at the World Health Assembly that year.

'ADI will be involved in all of these activities,' said Marc Wortmann, 'which is a chance for our members to obtain a stronger position with their governments.'

During the meeting, ADI representatives were also given the opportunity to speak about dementia during a side event organised by the International Alliance of Patients Organisations (IAPO), where Hussain, who is also Chairman of IAPO, talked about his personal experience of dementia.

ADI's experiences at this event have been very encouraging and, most importantly, have shown that the WHO are realising the importance of dementia as a global health problem and are enthusiastic about the positive effects that working in partnership with ADI will have on people with dementia and their carers across the world.

AUSTRALIA

Caring Places

In August, Alzheimer's Australia released *Caring Places: Planning for Aged Care & Dementia 2010-2050*, a report highlighting the shortfall in dementia care services the country will face unless the government

commit to reforms of the current system and budget.

Since Australia's government made dementia a national health priority with allocated funding in the 2005/06 budget, around 8,500 community packages and residential places have been created each year. However, the report warns that, to keep up with demand, this figure would need to double to 17,000. Alzheimer's Australia predict that the number of people with dementia is set to rise from 257,000 today to over 981,000 in 2050 and, unless the budget is increased to allow for services to reach more people, many will have to cope without help.

The report describes how the country's government had not taken into account the rise in numbers of people with dementia when deciding on the amount of care packages and places in care homes to make available, focusing instead on the number of Australians over the age of 70.

Government appeal to the WHO

Following an appeal to the Australian government for dementia to be included on the agenda of the Western Pacific Regional Committee of the World Health Organization this year, an encouraging response was received from the country's Minister for Ageing, Hon Justine Elliot.

Hon John Watkins, CEO of Alzheimer's Australia New South Wales, was informed that The Department of Health and Ageing had contacted the Western Pacific Regional Office about this matter. Although the appeal was unsuccessful, the department stated that they would continue to seek opportunities to have dementia added to the agenda in the future.

USA

Alzheimer's Action Summit 2010

On 7-9 March, the Alzheimer's Association held their 2010 Alzheimer's Action Summit, an annual event marking the peak of the Association's ongoing advocacy work.

This year, over 600 supporters gathered on Capitol Hill in Washington, D.C. for the Summit, to campaign for the United States Congress to make Alzheimer's a national priority. During the Summit, members of the Association's Advocacy Forum attended more than 300 meetings with Congress, sharing their personal stories and national statistics. The focus of these meetings was on the promotion of four Acts, which would improve dementia research, diagnosis, care and treatment. This cause was further supported by thousands of email letters, which were sent online through the Association's website.

As part of the Summit, a Candlelight Tribute Rally took place on 7 March on the steps of the Lincoln Memorial in Washington, D.C. The Rally saw a large number of advocates gathering to light candles in honour of friends or family members. An accompanying virtual rally was available online following the Summit

Advocates met members of Congress to promote improved dementia research and services



and 12,000 tributes were made over four days on the Association's dedicated website.

7

Social Security Administration

On 11 February, the Social Security Administration (SSA) in the USA announced that early-onset Alzheimer's had been added to the Compassionate Allowance Initiative, giving those with the disease access to Social Security Disability Allowance and Supplemental Security Income. The Alzheimer's Association were instrumental in encouraging this decision and thanked the SSA by awarding their 2010 Humanitarian Award to SSA Commissioner Michael Astrue during the Alzheimer's Action Summit.

Changing the Trajectory

On 19 May, the Association released Changing the Trajectory of Alzheimer's Disease: A National Imperative as part of their appeal to the government to support the National Alzheimer's Project Act, which, if passed, would see the formation of a National Alzheimer's Project Office and inter-agency Advisory Council to develop a national plan for Alzheimer's.

The report contains evidence that the cumulative cost of caring for people with dementia in the USA between 2010 and 2050 will exceed \$20 trillion dollars and estimates that the number of people with dementia will increase to 13.5 million by 2050. The report also suggests ways in which savings could be made if better treatments were available.

Continued on back page...

Advocacy Special

Advocacy developments

During the Alzheimer University on advocacy in Chicago, members shared news of their own advocacy developments. Here are details from some of those who attended, and other ADI members across the world

sionals in the area to improve the current situation.

Iran

Iran Alzheimer's Association is currently working in collaboration with the country's Ministry of Health to prepare the first draft of a National Dementia Plan. It has now been decided that this Plan, which includes developments in education, research, treatment and care and support services for people with dementia and their families, will be piloted in Tehran.

Barbados Barbados Alzheimer's Association is currently working with government agencies to lobby for the country's government to recognise dementia as a chronic disease. **Argentina** In late August, Ana Maria Baldoni, President of Asociación de Lucha contra el Mal de Alzheimer, joined the Ministry of Health and professionals working with older people in the country, to discuss the issues surrounding dementia in the Argentina. A secretary of the Policies of Formation and Inclusion offered an encouraging statement in the lead up to the meeting, emphasising that the aim was to work with profes-

Pakistan

Alzheimer's Pakistan is approaching likeminded organisations in Pakistan, such as Pakistan Medical Association and Concerned Citizen of Pakistan, to develop a stronger base for their advocacy work. The association also continue to meet with the relevant governmental departments to highlight the issues surrounding dementia in the country.

Japan

Alzheimer's Association Japan (AAJ) has maintained good contact with its national government and, in particular, the head of the dementia section of the Ministry of Health, Labor and Welfare, Mr Toshihiko Miyajima, whose mother has dementia. The Japanese government is also preparing a revision of long term care insurance to be enforced from 2012 and AAJ is lobbying for certain points to be considered in the development of this.

TADA Chinese Taipei

Since 2004, TADA has successfully managed to develop an early intervention service for people with dementia. This service has been chosen by the government as the focus of subsidisation of elder service in 2010.

New Zealand

As part of its *People, Policy*Partnerships conference, held in

May 2010, Alzheimers New Zealand
launched its National Dementia

Strategy at a Parliamentary reception.

The Strategy was developed in collaboration with all internal and external sector stakeholders and presented to the country's Minister of Health.

Alzheimers New Zealand is now working to encourage the government to make dementia a national health priority.

India

The Alzheimer's and Related Disorders Society of India are currently developing a National Dementia Strategy. Regional consultations were held to discuss this and were followed by a national meeting in Delhi, with the results being presented in March. The final *Dementia India* document will be released during the National Alzheimer Summit to be held in Delhi on World Alzheimer's Day.

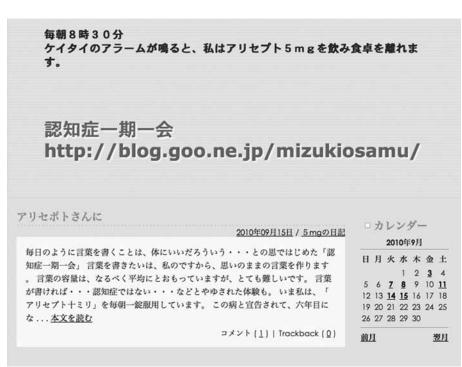


Living with dementia

Ninchisho Ichigoichie (Cherished Encounters)

Osamu Mizuki, Japan

Osamu Mizuki is 73 years old and was diagnosed with Alzheimer's disease five years ago. Impressed by Christine Bryden's book, Who will I be when I die?, he began writing his blog in 2006. He has many readers and exchanges messages with them on his website. Osamu Mizuki's blogs written from 2005 to 2006 were edited by AAJ (Alzheimer's Association Japan) and published in 2006. Below are two of his most recent.



August 6 2010

Challenging difficulties today and keeping dreams for tomorrow

There is an expression "heat blur" I am sure it's true.

The heat got to me and I'm not in the best shape.

I am struggling continuously as I am writing this now.

Five years have passed since I have been diagnosed with Alzheimer's.

It seems that I am getting senile.

It is difficult for me to put my feelings into words.

But I do not give up writing.

I genuinely want to do everything to the best of my ability.

Challenging difficulties over and over again and keeping hopes and dreams for tomorrow.

Then life goes on.

September 3 2010

I have friends. That is why I can write more

It is still hot but there is a hint of autumn in the air

It has been extremely hot this summer and I have suffered from it.

The word September and my feeling about September do not seem to be exactly the same.

I would have been happier if I could write fluently.

What I write shows what I am.

I write so carefully but there are many misspelled words.

So I rewrite dozens of times.

Why don't the words come?

I tap on my head to pull out suitable words.

Surprisingly, tapping is effective.

Tapping softly, gently.

Autumn breeze will ask me "How is it going?"

Fully appreciating the words, I can feel I am not alone and keep my chin up.

I have friends. That is why I can write more.

I say to myself "lighten up".

■ Research Update

Global Perspective September 2010

Cognitive Stimulation Therapy

Martin Orrell, Professor of Ageing and Mental Health, University College London and North East London Foundation Trust, UK

Cognitive Stimulation Therapy (CST) was developed from Reality Orientation and a systematic review of clinical trials of Reality Orientation for dementia. The large randomised controlled trial of CST (Spector et al, 2003) found that the CST groups could improve cognition and quality of life for people with dementia. The benefits of CST for cognition compared favourably with trials of cholinesterase inhibitors for Alzheimer's disease, and the economic analysis showed that CST was likely to be cost-effective.

In the UK, the 2008 National Institute for Health and Clinical Excellence (NICE) auidelines for dementia recommended that all people with mild to moderate dementia should be 'given the opportunity to participate in a structured cognitive stimulation programme'. A recent pilot study of weekly maintenance CST running for an additional 16 weeks, found a significant improvement in cognitive function for those receiving maintenance CST comparing to those receiving CST only. The study identified the need for a large-scale, multicentre randomised control trial to define the potential longer-term benefits of

Maintenance Cognitive Stimulation Therapy (MCST) for dementia. The SHIELD Maintenance Cognitive Stimulation Therapy is one of the research projects being carried out by researchers at the North East London NHS Foundation Trust in collaboration with University College London, Bangor University and the London School of Economics. It is part of the Support at Home: Interventions to Enhance Life in Dementia (SHIELD) programme, which is funded by the National Institute for Health Research.

CST is an evidence-based, brief intervention for people with mild to moderate dementia. It involves a number of structured sessions aimed to actively stimulate thinking and social engagement for people who have dementia. As CST is often carried out in a group, people also get the benefits of interacting with others and find the activities fun. Groups are usually run by someone who has been trained in the principles of CST. Each group lasts for about 45 minutes and follows a specific format, aiming to create continuity and consistency. The main topic varies from session to session.

If you would like further information about CST and the SHIELD project, please contact e.aguirre@ucl.ac.uk or visit www.cstdementia.com.

The CST Manual Making a Difference is available from Hawker Publications London at



www.careinfo.org/books.php

Each group opens and closes with introductions/farewell, a warm up/warm down activity and a familiar activity such as a song. The main activity changes each week. Different media and sensory experiences are used to aid communication and stimulate thought processes. For example, if the theme was childhood, a selection of childhood sweets (taste), songs (hearing) and games (touch) could be used.

The group should never feel like it's a memory test and people are encouraged to express opinions and feelings as opposed to facts. They may also reminisce about earlier, relevant experiences. Everyone is supported to contribute new ideas and thoughts as they are able. The sessions are adapted to people's abilities and wishes in order to make the most of their potential. Everyone's input is welcomed and valued. CST aims to provide a therapy that is both enjoyable and effective.

Get the latest dementia news at www.alz.co.uk

ADI have launched an international news feed, offering up-to-date news on the latest developments in research and the global dementia movement. The feed also includes news of ADI and member associations across the world, including articles in other languages.

So, if you want to stay informed about new developments in the global dementia movement, visit www.alz.co.uk.



Advocacy special

Continued from page 7...



Participants from Sri Lanka, Jamaica, Trinidad & Tobago and Puerto Rico were among the twenty-five association representatives at the Alzheimer University in June

Campaigning for change

In June, ADI held an Alzheimer University programme on campaigning in Chicago, USA. The event was well attended with twenty-five participants travelling from fifteen countries across the world to share their experiences of raising awareness and advocacy and to learn from each other.

During the programme, participants were given the opportunity to learn more about working with policy makers and the medical community, building strategy and using data to make a case, and the pros and cons of national Alzheimer plans.

An informative discussion took place during the event to establish the needs of each association and their current advocacy activities. Jessica Federer from Bayer and Carroll Rodriguez from the Alzheimer's Association in the USA offered advice on finding resources and fundraising for advocacy work and Mike Splaine from the Alzheimer's Association spoke to participants about the benefits and drawbacks of coalitions.

As part of the programme, participants were given the opportunity to meet the staff of the Alzheimer's Association head office in Chicago and spend some time learning about the Association's helpline, Early Stage Programme and Greenfield Library. Jerome Stone, Founder and Honorary Vice President of ADI, took the time to visit and spoke about the development and growth of ADI.

At the end of the programme, representatives from each participating association were asked to present a strategy action plan, based on what they had learnt during the event, to be implemented in their country. The event was a great success and ADI would like to thank Mike and Sandra Splaine for their hard work in planning and facilitating this event.

SCOTLAND

National Dementia Strategy launched

Scotland's first national dementia strategy was launched in June this year, signalling the government's commitment to improving the lives of people with dementia in the country.

The strategy, which was launched by Public Health Minister, Shona Robison at a Silver Seniors activity group, pledges that more support will be available to those who have just received a diagnosis of dementia and the standard of care for people with dementia in hospital will be improved. In order to show full commitment to the strategy, the Scottish government will also be required to continue supporting dementia research.

Henry Simmons, Chief Executive of Alzheimer Scotland, welcomed the news, but drew attention to the necessity of implementation, 'We cannot afford to get this wrong. The strategy is just the start – now is the time for real action on dementia.'

Obituary

Robert N Butler

ADI were sad to learn of the passing of Robert Butler on 4 July, aged 83. Robert was an active spokesperson against ageism and played a part in the founding of the Alzheimer's Disease Association in the USA, now the Alzheimer's Association.

Dr Butler was a physician, gerontologist, psychiatrist and author of the Pulitzer Prize-winning Why Survive? Being Old in America. His research into dementia introduced the world to the idea that dementia is not a normal part of ageing, an ethos that is still very important in the advocacy work of ADI and Alzheimer associations across the world.

At ADI's annual International
Conference in 2004 in Kyoto, Japan,
Dr Butler spoke about the need for
an official declaration of the rights
of older persons and for society
to both acknowledge the human
abuses of older people and adopt
measures to end them.

Dr Butler had a hugely successful career. He was the founding director of the National Institute on Aging (NIA) of the National Institutes of Health in the USA. During his time in this post, he established Alzheimer's disease as a national research priority at the NIA. He was also founding chair of the Brookdale Department of Geriatrics at Mount Sinai Medical School in New York.

In 1990, he founded the International Longevity Center (ILC) in the USA, as the first international research, policy and education organisation, with the aim of educating people on how to live better and longer lives. At the time of his death, Dr Butler was CEO and President of the ILC in the USA.

ADI extend their deepest sympathies to Dr Butler's family, friends and colleagues.