Alzheimer's Disease
International

June 2011
Volume 21 No.2

Global Perspective

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

The Changing Face of Dementia

ADI Annual International Conference

The city of Toronto, Canada's culturally vibrant metropolis, played host to ADI's annual international conference in 2011. Delegates from all areas of the dementia field travelled from far and wide to share their work and learn from the experiences and knowledge of others.

The conference Opening Ceremony set in motion this hugely successful event, with entertainment from a group of aboriginal dancers and a particularly moving performance from Canadian Broadway actress Louise Pitre. Delegates were invited to attend a Welcome Reception in the bustling and colourful exhibition space, where they could take part in a croquet match courtesy of Jiminy Wicket, learn more about the work of national Alzheimer associations across the world, or pick up their free *Puzzle With Me* puzzle, designed with people with dementia and their carers in mind.

A host of well-attended plenary sessions covered such topics as prevention, the public health agenda, emerging approaches in psychosocial research and new developments in Alzheimer's disease. Presentations on methods and programmes in place for reaching ethnic minorities and indigenous communities were also a highlight of the programme.

The Murray Alzheimer Research and Education Program (MAREP), based at the University of Waterloo in Canada, hosted *A Changing Melody Forum*, an inspiration session, which gathered together people with dementia, carers and professionals to discuss a range of issues such as stigma, adapting to change and enabling people with dementia. The session was a great success and provided an opportunity to meet new people and share experiences in the lead-up to the conference.


PHOTO IRENE BORINS ASH

A Canadian aboriginal group welcomed delegates during the Opening Ceremony

CONTINUED ON PAGE 4 ...

ADI calls for non-communicable disease inclusion

A summit on non-communicable diseases (NCDs), which will be hosted by the United Nations General Assembly in September, was the topic of discussion at a session during ADI's annual International Conference in March, most notably for the absence of dementia on its agenda.

The Summit will involve Heads of State and representatives from across the world, who will meet to discuss the threat NCDs pose in low and middle-income countries. The four disease areas included are currently cardiovascular disease, diabetes, cancer and chronic respiratory disease, but as yet there has been no mention of dementia being addressed.

With the predicted increase in people over the age of 60, who will be at risk of all NCDs including, most importantly, dementia it is a key factor for the 21st century's social and economic sustainability, and should therefore be an essential component of the UN's NCD considerations.

In response to the initial UN resolution, ADI, in cooperation with HelpAge International, the International Longevity Center and ADI member associations in lower and middle-income countries, contacted the Alliance to state the case for dementia.

Efforts are continuing to push for dementia to be included in September's Summit. An update on this progress will appear in the next issue of Global Perspective and regular updates can be found on the ADI website at www.alz.co.uk

To view ADI's declaration on the NCD Summit, visit www.alz.co.uk/news/ncd-declaration

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 Friday 29 July 2011.

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Editorial

Daisy Acosta, Chairman

It cannot be denied that there has been a real buzz surrounding the global dementia movement so far this year. The lack of inclusion of dementia in the United Nations' Non-Communicable Disease Summit has stirred everyone into action once more and, with such huge support from our members and working alongside like-minded organisations, I am confident that our message will get across and dementia will receive the recognition it desperately needs and deserves. The ADI conference in Toronto, Canada, in March offered many groups and individuals the opportunity to join together to discuss what action can be taken. At a time like this we are reminded of the great importance the ADI conference plays in making our work the success that it continues to be. It was great to see so many familiar and new faces in Toronto and I hope you all enjoyed the conference and left feeling inspired to continue your work. Thank you to all those who contributed to making the conference the great success that it was.

Events

2011

16 – 21 July 2011
Alzheimer's Association International Conference on Alzheimer's Disease (AAICAD)
Paris, France
Phone: +1 312 335 5790
Email: icad@alz.org
Web: www.alz.org/icad

6 – 9 September 2011
International Psychogeriatric Association 15th International Congress
The Hague, The Netherlands
Phone: +1 847 501 3310
Fax: +1 847 501 3317
Web: www.ipa-online.net

6 – 8 October 2011
21st Alzheimer Europe Conference
Moscow, Russia
Tel: +35 229 7970
Fax: +35 229 7972
Email: info@alzheimer-europe.org
Web: www.alzheimer-europe.org

18 – 20 October 2011
V Congreso Iberoamericano sobre enfermedad de Alzheimer
Havana, Cuba
Email: scual@informed.sld.cu
Web: www.alzheimercuba.com

13 – 16 October 2011
The 5th World Congress on Controversies in Neurology (CONy)
Beijing, China
Tel: +972 3566 6166
Fax: +972 3566 6177
Email: info@comtecmed.com
Web: comtecmed.com/cony/2011

18 – 20 October 2011
V Congreso Iberoamericano sobre enfermedad de Alzheimer
Havana, Cuba
Email: scual@infomed.sld.cu
Web: www.alzheimercuba.com

20 – 23 October 2011
Seventh International Congress on Vascular Dementia
Riga, Latvia
Tel: +41 22 908 0488
Fax: +41 22 906 9140
Email: vascular@kenes.com
Web: www.kenes.com/vascular

1 – 3 November 2011
The 6th UK Dementia Congress
Liverpool, UK
Email: shital@hawkerpublications.com
Web: www.careinfo.org/uk-dementia-congress.php

8–10 November 2011
14th Asia-Pacific Regional Meeting of ADI
Bangkok, Thailand
Email: mcpc.thailand@hotmail.com
Web: www.azthaimeeting.com

2012

7 – 10 March 2012
27th Annual International Conference of Alzheimer's Disease International
London, UK
Tel: +44 870 458 4171
Fax: +44 870 442 9940
Email: adi2012@mci-group.com
Web: www.adi2012.org

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

The time to say goodbye

Federico Ortiz-Moreno, social psychologist, Mexico

Living with a person with dementia is not easy, but we should not make it more difficult for ourselves. Certainly, the burden is heavy because there are the physical, emotional, financial, social and environmental factors that make you feel bad, but it is also a great lesson that reminds us of the value of life.

On a personal level it helped me a lot. It helped me to learn and understand that there are many people in need for whom something can be done. It helped me to form an Alzheimer association that has lead to several support groups in my hometown, several other associations in my country and even abroad, but more than that, it helped me to appreciate what life is; what we are, what we do for our loved ones, ourselves and others.

To me, the three stages of Alzheimer's disease are all important and each brings us to a special situation in our lives.

The first stage is the one of forgetting, where we are just learning what memory is, or the lack of it. A stage where we notice 'something' happens without realising fully what it is, that memory is being lost by a degenerative disease and that these symptoms are not carelessness, distraction or simply a person's character.

Then, there comes a second stage. It is very hard to bear because the person becomes anxious, angry, wants to leave the house alone, does not understand, and every day the situation brings us to the brink of despair. We want the person to understand us, while it should be the other way around. We need to understand that he or she no longer lives in the world in which we live. Despite this, men and women are still individual people. They deserve all the respect and affection that we can provide.

Finally, it comes to that stage that, I think, is very sad and painful; when we know that everything is ending, when we feel completely powerless, helpless, not able to do something for someone who we saw with great force and energy and is now being lost into a world of silence and forgetfulness.

> *It's been a hard, while at the same time a wonderful, experience to provide care*

What can we do about this? Well, many things! It is not enough just to pray and ask God that everything is resolved. No, we must also prepare ourselves for his or her departure and know how to say goodbye to them. Knowing that sooner or later they will go and what we are doing for them here and now are both really important.

'In life, brother, in life.' You have to give love now and do not remember them with sadness later on, when they are dead, when there is nothing to be done.

Of course, many families are reluctant, and I know that sometimes it is very difficult to let them go, but we must. Just as, at first, it is difficult to accept the disease and, in fact, many families do not accept it. The same is true when it comes to accepting that they eventually have to go.

It is easy to say I have lived 45 years having my father with Alzheimer's disease and other members of my family with the same problem. It is easy to say, but it is also very hard to face it as a son and as a family member.

I have had the experience of living every stage of the illness with my father, who died in June 1998. I personally think it's been a hard, while at the same time a wonderful, experience to provide care.

He and his illness allowed me to appreciate what life is about, knowing that, despite the bad days and the bad times, the endless hours of anguish, anger and anxiety, there was always something to learn from that beloved person even though he had lost his cognitive abilities.

As a final message I would give the following message to all families, carers, and staff in the health care field:

- There is still too much to be done. Although the person is no longer the same as before, there is still too much to do, especially if they are in the first stage.
- Enjoy them right now while you have them. Yes, because although they suddenly appear not be with us or become aggressive, they are still human beings and need love, affection and security. We are the only ones who can give it to them.
- Learn to say goodbye to them. The disease is very hard and the farewell can be hard. We also need to learn to say goodbye. Sooner or later, they will no longer be with us.
- 'In life, brother, in life!' Love him, love them. Enjoy them. Tell them this right now, do not wait until they are six feet underground to say you loved them.
- You are not alone. Perhaps there will be some times you will be alone or feel very lonely, but there is always someone who can understand you and appreciate you, understand your feelings and be with you.

The disease is hard, I know, but it is harder to forget.

Federico is the founder of the Alzheimer's Association of Monterrey Mexico. His father and two other relatives had Alzheimer's disease.

Conference report continued from page 1

Delegates were also invited to attend a series of ADI workshops covering a range of topics aimed particularly at those from national Alzheimer associations. Examples of Alzheimer Cafés managed by ADI member associations were presented, the 10/66 Dementia Research Group presented their latest findings, and advice was offered from more established Alzheimer associations on coping with organisational growth.

The conference Closing Ceremony saw the Alzheimer Society of Canada handing the baton over to the Alzheimer's Society, who will co-host the next ADI conference, which will take place from 7-10 March 2012 in London, UK. For more information about this event please visit the conference website at **www.adi2012.org**

PHOTO IRENE BORINS ASH

Debbie Benczkowski from the Alzheimer Society of Canada signs a partnership agreement with the Canadian Institutes of Health Research during the conference

ADI is grateful to the Alzheimer Society of Canada, the organising committees, exhibitors and sponsors, and everyone who participated in the conference.

Many of the plenary presentations from 2011 are now available to view on ADI's website at **www.alz.co.uk/conference**

Results of the third Alzheimer Award

On 28 March, ADI and Fondation Médéric Alzheimer (FMA) announced the winner of the 3rd Alzheimer Award for evidence-based psychosocial interventions for people with Alzheimer's disease and their carers.

Sube Banerjee (centre) with Fabrice Gzil from Fondation Médéric Alzheimer (left) and ADI Executive Director Marc Wortmann

Sube Banerjee, Professor of Mental Health and Ageing at the Institute of Psychiatry, King's College London in the UK, was chosen to receive the award by a panel of judges which included a person with dementia, a carer, professionals in the dementia field, last years' award winners and representatives from FMA and ADI.

The winning project, *The Croydon Memory Service Model – early and effective diagnosis and intervention for all*, aims to provide early diagnosis and effective intervention for all people with dementia. It is based on the belief that the earlier dementia is diagnosed, the greater the chance the person with dementia and their family carers have to plan their future and avail themselves of the help, support and treatments (social and psychosocial, as well as pharmacological) which are available. The Croydon Memory Service Model is a multi-agency approach with joint ownership by health services, social services and the Alzheimer's Society in the UK. The evaluation of the intervention was positive and showed an increase from 15% of the people in the area being diagnosed early to at least 66%. The evaluation also showed that the service can increase the quality of life of those referred and that the work is cost effective as well as clinically effective.

The dissemination plan for the project is now to generate a simple information package on paper and online and make these available nationally and internationally.

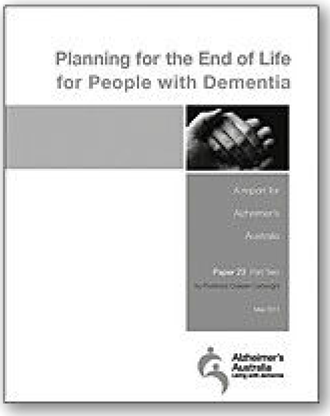
The 4th Alzheimer's Disease International and Fondation Médéric Alzheimer Award will shortly be launched. More information about the award can be found at **www.alz.co.uk/award**

Members' forum

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

ALZHEIMER'S AUSTRALIA

Planning for the End of Life for People with Dementia



Planning for the End of Life
for People with Dementia

Alzheimer's Australia

The development of a guide for planning a person's end of life has been long overdue in Australia. There is confusion about what options are currently legally available and the rights of a person in Australia to refuse treatment.

As a result many individuals may postpone thinking about this difficult but important issue. This has been reflected in market research with almost half (49%) of those surveyed having not considered end of life care plans in the event they lose their ability to make decisions for themselves[1]. Drawing up a will was the most preparation that many had completed (42%)[1].

Alzheimer's Australia has now developed and released *Planning for the End of Life for People with Dementia* to explore the options and issues for planning end-of-life care. The discussion paper was written in two parts by Professor Colleen Cartwright, director of the ASLaRC Aged Care Services Unit at Southern Cross University and commissioned by the National Consumer Advisory Committee of Alzheimer's Australia.

Part 1 is a guide for planning end-of-life care options within the current law and recording the decisions of an individual so they will be respected when the time comes. These include decisions about wills, enduring guardianship and power of attorney, trusts, advance care directives, palliative care and organ donation. The first paper also explains the rights that a person has to refuse treatment, food or fluids, antibiotics and resuscitation in Australia.

It is clear that advance care planning is critical to a good death. Equally, if the present system in Australia is to work better for people with dementia and their family carers, more resources are needed for palliative care in the community.

Part 2 is a discussion paper on options not legal in Australia currently, such as euthanasia. Alzheimer's Australia has no position on euthanasia but developed the paper to provide education and information about the arguments and issues surrounding all sides of the debate. The paper presents some of the special issues in euthanasia for people with dementia. The objective is to reduce the confusion that clouds the debate of euthanasia including what is and what is not euthanasia.

Alzheimer's Australia has recommended that more education and services designed to promote end-of-life planning are needed for the Australian community and has placed this firmly on their agenda for the next year.

Copies of both parts of this report are available from the Alzheimer's Australia website: **www.alzheimers.org.au**

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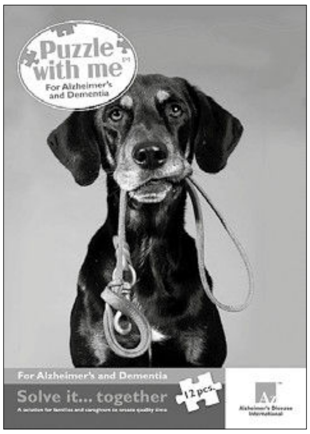
[1] Pfizer Health Report Wave 2 Views and understanding of Alzheimer's Disease in Australia October 2010 Prepared for Pfizer Australia by StollzNow Research page 45

Solve it ... together

As her mother's Alzheimer's disease progressed, Jane Snyder found communicating and connecting with her increasingly difficult and she struggled to find new activities that they could share. While searching for more suitable options, Jane discovered the lack of large-piece puzzles for mature adults and this marked the beginning of *Puzzle With Me*.

***Puzzle With Me* provides people with dementia and their carers with the opportunity for verbal and non-verbal communication. The task of putting together a 12-piece puzzle with images that are more appealing and familiar to adults, such as landmarks, hobbies and pleasant scenes, encourages conversation and connection between the person with dementia and carer.**

The puzzles, which were officially launched at ADI's annual International Conference in March, are currently available in nine different designs and ten percent of all sales will go to ADI. Visit www.puzzlewithme.com to find out more.



One of the puzzle designs from the range

Members' forum

CONTINUED

HONG KONG SAR

Helping children spot the signs of dementia

Students and people with dementia take part in one of HKADA's activities

Hong Kong Alzheimer's Disease Association, in collaboration with schools' parent teacher associations and the Salvation Army, have developed a training programme for schoolchildren which will help them to recognise the signs of dementia.

The project, which was conducted in Tai Po where almost 10% of the population are senior citizens, saw 2000 questionnaires sent to 20 primary and 23 secondary schools. Children were asked to complete the questionnaires, which focussed on their elder family members, with their parents. An impressive 92% of the surveys were returned. As a result of this project, 81 people received cognitive assessment and seven were referred. Family doctors in Tai Po were also offered training in how to diagnose dementia.

Planning is now underway for the project to be extended across the country. It is believed that this project could also be used in other countries to educate children and help those people with dementia who have not been diagnosed to access care and treatment.

This project is just one of the ways in which Hong Kong Alzheimer's Disease Association are bringing together people with dementia and young people.

www.hkada.org.hk

IRAN

Iran's first day centre

Staff at Iran Alzheimer Association's new day centre coordinating an art activity

Iran Alzheimer Association was pleased to announce the inauguration of their first day centre earlier in the year. The centre, which covers an area of around 250 square meters, already has 15 registered clients who visit three times per week. The centre offers a range of services and activities, including physiotherapy and art and speech therapies.

Early reports from the centre have shown that the standard of service is very good and the clients' families are pleased with the new facility.

www.alzheimer.ir

LEBANON

Building capacity

In partnership with the Ministry of Social Affairs, Alzheimer's Association Lebanon have developed a full capacity building programme of events and activities to educate and raise awareness within the country's communities and health care professionals.

The Capacity Building programme in Alzheimer's Disease, which will take place in early August, will consist of six workshops covering all Lebanese territories, Public Health outreach activities, a region-specific and community-centred needs assessment programme and the development of an educational toolkit, which will be sent to designated public and private community organisations.

The programme will also involve data collection and analysis with study results being published in the public domain and peer-reviewed journals. A white paper will also be developed and sent to the Ministry of Social Affairs, the Ministry of Health and the Council of Ministers on the state of elderly affairs across Lebanon.

It is hoped that this programme will result in a heightened level of awareness of dementia within the country, improved standards of care for people with dementia and the formation of Alzheimer's Association Lebanon chapters in various territories.

www.alzlebanon.org

SCOTLAND

Memory Bus launched

Falkirk Provost Pat Reid, left, and Chief Executive of Alzheimer Scotland, Henry Simmons, launch the new Memory Bus

Reaching out to those in rural communities is an issue for many national Alzheimer associations. To address this Alzheimer Scotland launched their first Memory Bus in February to travel around the country providing information to those in the most remote areas of Scotland.

During its tour the bus will visit various locations, including shopping centres, car parks, village halls, farmers' markets and high streets in both rural and urban areas. The bus will act as a mobile information unit, whilst also helping the association to raise awareness of dementia and their work throughout Scotland.

Henry Simmons, Chief Executive of Alzheimer Scotland commented

'The launch is just the start of what will be a grand tour for Alzheimer Scotland's latest venture. We want to make sure that no one goes through dementia on their own.'

www.alzscot.org

ROMANIA

First conference a success

The first National Alzheimer Conference in Romania took place in February, marking a real boost to the awareness and advocacy efforts of the Romanian Alzheimer Society.

Under the heading *New Insights into Dementia,* the conference covered a broad range of topics, including European policies and legislation, risk factors, biomarkers, treatment, and end-of-life care.

Representatives from the Society have accelerated their efforts to improve dementia care and support services in the country in recent months. A press conference, organised by the Society, took place in April with a strong message aimed at the government to develop a national dementia strategy.

During the press conference, Catalina Tudose, President of the Society, announced plans to develop an *Alzheimer's Decalogue*, which would provide a range of dementia-related information, including standards of care issued by authorities, a national register of people with dementia in order to protect their rights, support regulations, and training and advice for families and professional carers.

www.alz.ro

Speakers at the Romanian Alzheimer Society's first national conference

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TADA CHINESE TAIPEI

New model home

TADA Chinese Taipei have successfully seen off competition from more than 30 groups who applied to use the private residence of the country's former President, Chin Shui-bian. The house was made available as a charitable offer last year and in now available, free of charge, to the association who have created a 'model home'.

'About 6 years ago, one family caregiver told me that it's not easy to go out with people with dementia because of the behavioural and psychological symptoms they experience,' commented Li-Yu Tang, Secretary General of TADA. 'She said that if there was one place specifically for people with dementia and their caregivers to visit, it would be very helpful to her. After that, more and more family caregivers expressed the same need.'

Both people with dementia and carers are welcome at the home, where activities frequently include singing, playing games, gardening, painting, exercise, talking, reading and watching old films.

The home has received some particularly strong feedback from people with dementia are carers alike.

www.tada2002.org.tw

A visitor at TADA's model home enjoys one of the many activities on offer

Dementia newsflash

France
French President, Nicolas Sarkozy, has confirmed his commitment to follow the country's current Alzheimer's plan with another when the first comes to an end in 2012.

Germany
Deutsche Alzheimer Gesellschaft called for more person-centred care through a documentary screened across the country in February.

The Netherlands
Alzheimer Nederland hosted the first Alzheimer's Tea House for Moroccans. Participants were provided with information in their own language and given the opportunity to speak to others and share experiences.

Turkey
In June, Turkish Alzheimer's Society will host a workshop on carpet weaving for people with dementia and carers across the European Union. The workshop will explore local culture and help to engage people with dementia

UK
Alzheimer's Society and Alzheimer Scotland have teamed up with Tesco, the world's third-largest retailer, to raise £5 million. Funds received will go towards building a better future for people with dementia in the UK and helping to raise diagnosis levels from just 40% by 2014.

Looming dementia epidemic in Asia

Dementia is increasing fast in Asia, placing a huge burden on a growing army of carers, who are mainly family members. Jane Parry and Cui Weiyuan report on how dementia is starting to receive the recognition it deserves.

China's population is ageing fast. Life expectancy in China has gone from 68.4 years in 1990 to 73.8 in 2008; combined with the one-child policy this development will lead to a massive demographic shift in the coming decades. The elderly support ratio, the ratio of people in the population aged 15 to 64 to those aged 65 and above, which was 9:1 in 2010, will become 3:1 by 2050, China's Population Research Bureau predicts. The proportion of over-65s to China's total population is estimated to rise from 7.8% in 2005 to 16.3% in 2030, according to data from the Organisation for Economic Co-operation and Development.

China has recognized that dementia will be a significant problem associated with an ageing population, but current initiatives will have to be scaled up fast to meet growing demand. So far there is not even a national estimate of the burden of dementia.

'There is a great challenge to get dementia on the health policy agenda, but much has been achieved in the past decade,' says Dr Huali Wang, vice chair and vice secretary-general of Alzheimer's Disease Chinese (ADC). This research and advocacy organization is working to get dementia higher up on the health policy agenda.

Alzheimer disease is the most common cause of dementia, but it is often used as an umbrella term for several conditions causing dementia.

'Dementia care was listed as one of the priorities of mental health services in the Mental Health Plan 2002–2010 and ADC is currently working with the medical community to get it included in the upcoming Major Mental Health Plan,' explains Wang. 'The government has realized the burden of dementia … but we need to take action to get a general estimate and we also need more investment in educating the media and government,' she says.

Current initiatives will have to be scaled up fast to meet growing demand

China's experience with this pressing public health issue is just one of several in Asia. Of the 35 million people currently living with dementia globally, 58% live in low- and middle-income countries and by 2050 this figure is projected to reach 71% of the total. Eastern Asia and southern Asia will see dementia growth rates more than double in the coming 20 years, Latin America will see increases of 134% to 146% and North Africa and the Middle East can expect a 125% rise, according to research by Alzheimer's Disease International (ADI).

High-income countries already have a sense of the cost of dementia. In 2010, north America and western Europe accounted for over two-thirds of the estimated US$ 604 billion worldwide cost of dementia, attributed almost equally to the indirect costs of informal care and the direct costs of medical and social care. In the rest of the world, informal caregivers bear the brunt of the burden. Medical and social support are underdeveloped or non-existent and the enormity of the looming dementia epidemic is not yet widely appreciated.

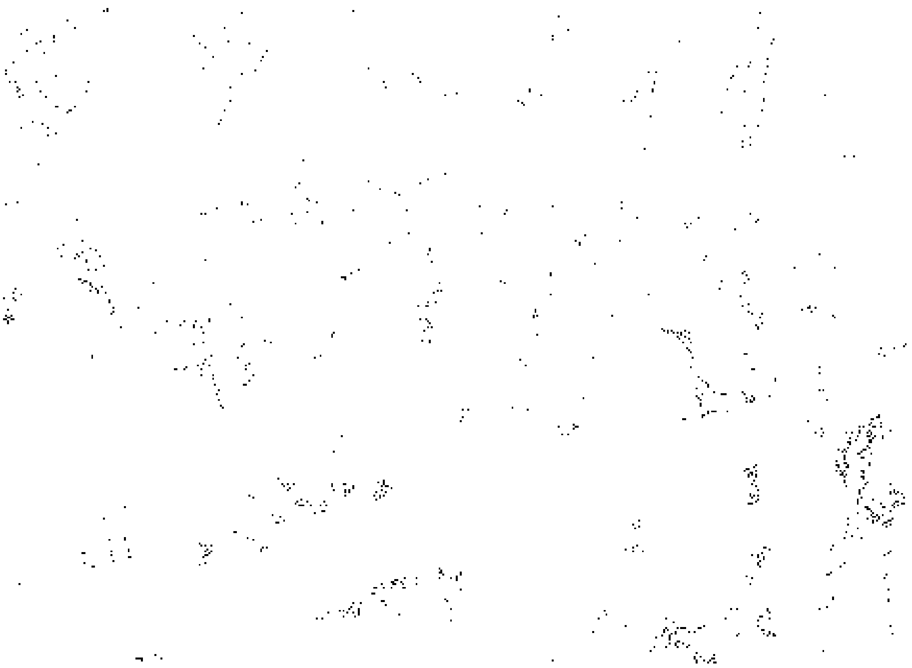
In the Asia Pacific region, only Australia, Japan and the Republic of Korea have formulated public health policies directly targeting the burden of dementia. Yet it is China and India that account for the lion's share of dementia prevalence in the region. Like China, India is waking up to this.

'It took quite some time to convince the officials of the need to include dementia in the list of conditions eligible for government support,' says Dr K Jacob Roy, national chairman of the Alzheimer's and Related Disorders Society of India. 'Our goal is to make dementia a national health priority, considering the fact that there are over 100 million people over 60 years of age and 3.7 million people with dementia.'

'The problem is that dementia is not yet integrated in primary care arrangements and it needs to be in the future,' says Marc Wortmann, executive director of ADI. The job of identifying elders showing signs of dementia usually falls on

Big thanks to MetLife Foundation

ADI would like to thank MetLife Foundation for their very generous support of World Alzheimer's Day and our advocacy work. This will enable us to continue work with our members to raise awareness of dementia around the world.



As yet China currently has no public health policies for dementia, though it accounts for the highest dementia prevalence rates in the region alongside India

relatives. This is particularly so in countries where primary health care is underdeveloped and screening programmes for cognitive decline cannot be implemented.

> *A host of creative interventions are being developed*

'In most parts of the world most people with the disease go undiagnosed,' says Wortmann. 'One of the problems in developing countries is … [the] lack of a primary care system.'

A recent WHO initiative to encourage countries to pay more attention to mental health problems is the mental health Gap Action Programme (mhGAP). The WHO mhGAP Intervention Guide was launched in October 2010. It is for use by health-care workers in the management of a range of mental disorders, including dementia. There are simple protocols and flowcharts, providing a guidance process for diagnosis and descriptions of psychosocial interventions including those for caregivers. Implementation of the programme has begun in a few countries, including Ethiopia, Jordan, Nigeria, Panama and Sierra Leone.

'In low- and middle-income countries specialist numbers are never going to be enough, and dementia care will need to involve community health workers, primary care doctors and nurses in a community-based programme,' says Dr Tarun Dua, a medical officer in WHO's Evidence, Research and Action on Mental and Brain Disorders unit.

'While the scale of the global dementia epidemic is daunting, the wide variety of responses at the grassroots level is cause for optimism,' says Wortmann. A host of creative interventions are being developed, from children in China's Hong Kong Special Administrative Region being trained at school to spot dementia in their grandparents, to a low-cost, home-based intervention in India to support families of people with dementia using locally available resources.

'My optimism has to do with the fact that we can do more than people think. We can use psychosocial interventions to give people a better quality of life, and there is enough in the pharmaceutical pipeline to assume that medical research will find something,' he says.

But in terms of developing dementia policies, most of the action is still in Europe. 'Developments in India are promising but we need to do more in Asia,' says Wortmann. 'Public awareness is growing but in most countries governments are not picking up on that and starting programmes.'

This is an abridged version of a report taken from the bulletin of the World Health Organization 2011;89:166–167. doi:10.2471/BLT.11.020311. Used with kind permission from the World Health Organization. Not to be re-printed without permission.

Yin Jiliang and his wife Su Zhiying at an award ceremony for Excellence in Home Care for People with Dementia in Beijing, China

COURTESY OF ALZHEIMER'S DISEASE CHINESE

Living with dementia

Teachable moments

Jim Mann, Canada

All it takes is one person, one incident to become an advocate.

For me, it was just a few months after my Alzheimer's diagnosis when I received a broadly distributed e-mail from a business acquaintance that began with, 'Even with my failing memory I don't recall.' I knew the writer didn't have cognitive impairment but I couldn't ignore this. I had to respond. So for the first time publicly I replied with 'I have Alzheimer's'. That was how my journey of advocacy began.

I couldn't ignore his comment nor could I slough it off as ignorance on his part. I felt I had to take advantage of this 'teachable moment' to break the cycle of ignorance and to change attitudes through education. One person at a time.

Why? Because for me it's self-preservation. It's respecting my own dignity. It is therapeutic and it's educational. It is being an advocate with a purpose. No matter where in the world, I think there is a stigma around dementia. You say you have Alzheimer's in a group of people and the room can become quiet. People can become uncomfortable and it seems to me for no other reason than the perception of Alzheimer's or related dementias. The stereotype.

Oh yes, that dreaded stereotype. You know it: a person in the final stages, a person who doesn't speak, and who is almost approaching 100 years of age. Call it a general lack of awareness, a misunderstanding, or in some quarters a stigma that is associated with Alzheimer's.

I can't remember how many times I have encountered a seat mate whether on a bus or an airplane who, when he or she hears I have Alzheimer's, will go through the Alzheimer's stereotype check list. And that's another 'teachable moment' when I can shatter the stereotype and educate one more person.

And you can do it too. Advocacy can be done by one person or it can be a group. It can be done quietly in the background or through loud demonstrations. It can involve meeting after meeting or it can be one meeting or one telephone call or even one letter. Advocacy is between you and the person with whom you are communicating. For you – for us – it can and should be personal.

There is such a thing as self-advocacy and that's what we need to think about. It's advocating on one's own behalf and boy-oh-boy do we need to make our voices heard. How else do people know what is happening in our world?

Who better to address this for our own benefit if not for others, than us? We – those of us with the disease and our care partners – have a story to tell. So why not share it? Believe me it's not a boring story!

Only by speaking out can we educate; we spread the net, as it were, of awareness. Awareness of living with Alzheimer's and all of what that entails. We know the story but others don't. And if we don't tell the story – our story – who will?

There is such a thing as self-advocacy and that's what we need to think about

Augmenting my self-advocacy efforts is my provincial Alzheimer society, the Alzheimer Society of British Columbia where I am a member of the Advocacy Committee, Honorary Editor of the newsletter written by and for people with a dementia called *Insight*, and I am on the board of directors.

The newsletter is a valuable resource and one recent issue was devoted entirely to the issue of self-advocacy. Feedback was positive and with its wide distribution I trust we will have many more advocates in our province. Our Advocacy Committee is taking advantage and further promoting getting involved to those of us with a dementia and our caregivers. To get inspired.

Although I am not technologically sophisticated and not on Facebook or Twitter or any other social network programme, I know our Society is, which is tremendous. Through both traditional and social media we can communicate and advocate locally, nationally, regionally, and internationally.

And that's a good thing.

Research update

Dementia – impact on relationships

Lynda Hogg

This study was funded by the Averil Osborn Fund of the British Society of Gerontology. It was conducted by Lynda Hogg, who lives in Scotland and was diagnosed with Alzheimer's disease in 2006

When people receive a diagnosis of dementia, life changes. The journey from pre-diagnosis onwards can be a long road. Life must still be led to the best of an individual's ability. For some, this is a bewildering experience, fraught with uncertainty. This study explores how this affects a couple's relationship and in what way.

Methodology

Couples were invited from all over Scotland, through an advertisement in Alzheimer Scotland's newsletter, to take part in the study and a total of ten decided to participate. The ages of the couples ranged from late fifties to late eighties. Of the ten partners, seven people had been diagnosed with Alzheimer's disease, one with frontal lobe dementia, one with a mixed dementia and one with Lewy Body. There were eight men and two women. It was imperative that only one person in a couple had a diagnosis of dementia, as it would spoil the outcome of the research if both partners had the illness. This was because both collaborators' perspectives were needed to determine the impact dementia had on the relationship. In this study, both the person with dementia and their partner's answers were of equal importance.

People were initially contacted by telephone to be given a brief overview of the study and appointments were then arranged in writing. There were two visits to each participating couple; the appropriate consent was sought and forms signed on the first visit and the interview carried out on the second visit. Each person was also provided with an information sheet about the study and questions were answered or explanations given when asked. It was emphasised that anyone could withdraw from the study at any time, without giving an explanation. Both members of a couple had to be willing and able to take part. Each interview was recorded to be transcribed and analysed later.

The interviews were semi structured and conducted in the comfort of the couples' own homes. A questionnaire was designed, divided into four sections: *pre-diagnosis*, *at diagnosis*, *post-diagnosis* and *ongoing situation*. A pilot study was carried out to test the validity of each question; a small number of questions had to be altered before the study commenced and some wording simplified. Each interview lasted between 50 and 80 minutes. The questions were pertinent to bringing out the theme of the impact dementia has on relationships. As a person with a diagnosis of dementia, I am well aware of the sensitivities of the partner with the diagnosis and the need to allow time to absorb a question and to formulate a response.

Analysis

Each interview was transcribed in full and studied on an individual basis. Notes were made on different coloured paper and stapled to the transcription to capture significant data on the impact dementia has on relationships from pre-diagnosis to the ongoing situation. The transcript was read twice, firstly for an initial assessment and notes and secondly to verify the validity of the data.

The data was then divided into the responses of the person with a diagnosis and their partner separately. The coloured notes were then looked at for each, to decide if any response matched both the person with the diagnosis and their partner, or if the colours indicated a conflict of opinion, on the impact dementia has on a relationship. This was repeated for all ten transcripts.

All transcripts were looked at for a third time and the coloured notes for all the participants were studied to ascertain if there were any emerging threads between the couples and their experiences. The publication *How to Analyse your Data – A Practical Guide to Research Methods* assisted in this process.

Conclusion

At the core of this study is the fundamental difference in outlook of the person with a diagnosis of dementia and their partner. Lack of insight on the part of the person with a diagnosis is a huge factor. It is telling that the person with dementia will tell you what they can still do and the partners' take is that they actually cannot. For example, in the case of Keith and Amy, Keith does not think their relationship has evolved into carer and cared for. Amy is pleased that she must be caring in a way that Keith is not noticing. What Paul can do is at variance with what Sarah knows he can do. All of this can put a strain on a relationship. All of the relationships have developed into carer and cared for to varying degrees, despite the outlook of the person with the illness and this will continue to evolve as the illness progresses. The carer in the relationship loses themselves to some extent because of the dual role of partner and carer. In some instances it is difficult to find time for themselves without arranging cover, if they want to do something. The whole landscape of these people's lives has changed. Isobel states that Martin needs constant supervision and she is curtailed and something happens on a daily basis. The impact that dementia has on relationships is manifold, as the small couple snapshots of life with a diagnosis of dementia depict.

To read the full report visit www.alz.co.uk/news/dementia-and-relationships

ADI welcomes new Chair-Elect

Jacob Roy

ADI is pleased to announce that, following the annual Council meeting in March, Jacob Roy from India has been elected as the next Chairman of ADI, and will take over from Daisy Acosta in March 2012. Jacob is the founder and Chairman of the Alzheimer's and Related Disorders Society of India (ARDSI).

Jacob has proven his commitment to ADI since 1992 when ARDSI was formed and has taken up positions on ADI's Elected Board, nominations and conference committees, and as Vice Chairman. He also played a key role in ADI's 1998 annual International Conference, held in Cochin, India.

ADI would like to congratulate Jacob on his new post and we look forward to working with him more closely from 2012.

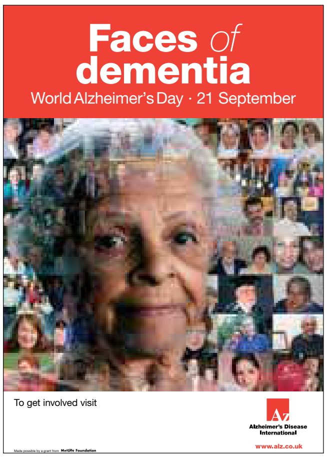
World Alzheimer's Day 2011

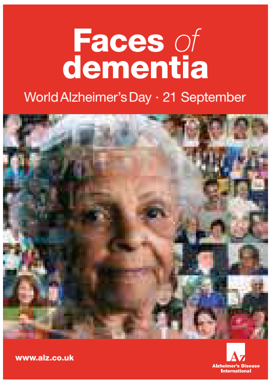
Faces of dementia is the theme for World Alzheimer's Day 2011. Preparations are already underway across the world to build upon the success of last year's events and activities. This year we are asking if you recognise the face of dementia while paying tribute to those who represent the 'Faces of dementia' in all parts of the world and working tirelessly to promote increased support and care for people with dementia and their carers.

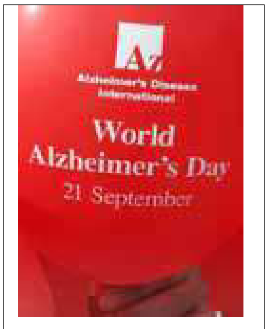
Every year on 21 September Alzheimer associations across the globe unite to recognise World Alzheimer's Day and 2011 will be no exception with events taking place internationally. We are confident that the large numbers of people involved and the media coverage these events will gain can make a real difference for people with dementia, their families and carers worldwide.

ADI is currently working closely with people with dementia to set up a new website where people with dementia and national Alzheimer associations can share event and activity ideas in preparation for World Alzheimer's Day. This website will be accessible through the ADI website and more details will be available soon.

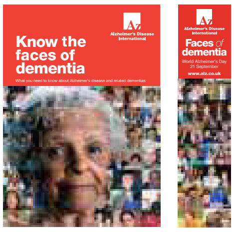
To find out what is happening in your country this year or to read a report of the many successes of World Alzheimer's Day 2010 visit www.alz.co.uk/WAD

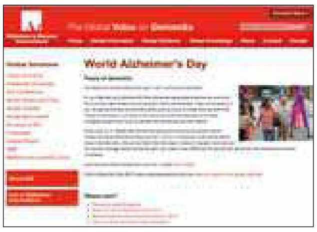






Toolkit
World Alzheimer's Day™ 2011





Campaign materials include a booklet *Faces of Dementia* with frequently asked questions – and answers – about dementia

'Three conferences in one'

The 27th International Conference of Alzheimer's Disease International will take place in London, UK, 7 – 10 March 2012

AZ INTERNATIONAL CONFERENCE
LONDON 2012
Alzheimer's Disease International

The event, co-hosted with Alzheimer's Society in the UK, promises to offer three conferences in one under the theme *Science, Fact, Fiction*, and will cover the many facets of dementia worldwide.

London will be an exciting city in 2012 and, by March, final preparations for the Olympics, which will take place close to the conference venue just a few months later, will be well underway.

We do hope that you will join us in London for this conference, which will have something for everyone. For more information about the conference and to register to receive regular updates on abstract submission, the conference programme and registration visit the conference website at www.adi2012.org