



Global Perspective

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

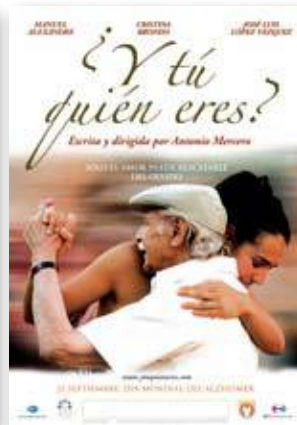
Dementia hits the big screen

The last few years have seen the release of several high profile films that depict the impact of dementia on the individual and the family. Most recently, Julie Christie's recent Academy Award nomination in the US for best actress in *Away from her* has directed the spotlight towards her moving portrayal of a woman with Alzheimer's and the difficult choices faced by her and her family.

This period of interest in mainstream films began back in 2001 with the success of the film *Iris*. Acclaimed actors such as Judi Dench and Kate Winslet both received nominations for high profile awards around the world.

Orien Reid, Chairman of ADI, commented 'It is exciting because these star-studded films and others are raising awareness about dementia through poignant stories of love, dignity and commitment. They have provided realism along with information and education. This ultimately may reduce stigma of dementia and result in early diagnosis and improved care.'

Looking beyond Hollywood there have been an increasing number of feature films that have been released around the world that have focused on the subject of Alzheimer's and dementia. The Indian 'Bollywood' film industry is one of the largest film producers in the world and reaches a mass audience within India and beyond. Famed for their melodramatic plots, the Indian film



Three recent films about dementia: *Away from her*, *¿Y tú quién eres?* and *Thanmatra*

industry have released two very high profile films, *Black* and *Thanmatra* which have depicted the effect of Alzheimer's disease on the life of an individual and their family and portrayed beautifully the themes of compassion and enduring love.

Within India the family has long been held as a respected institution and elders are generally cared for by their children and grandchildren. This being the case, dementia can often be hidden within the family, with members reluctant to look for outside help. Having the subject of dementia depicted through such an important medium as film, can provide a window to a wider audience who would not necessarily be fully aware of the subject matter or may have some misconceptions of dementia.

Jacob Roy, Chairman of Alzheimer's and Related Disorders Society of India (ARDSI), says 'There is such a culture for going to see

films in India, it is a relatively low cost pastime and therefore reaches a huge varied audience. We must acknowledge the role played by these films to raise awareness and reduce stigma in India. This is a good example of what good the media can do, we have had an incredible response from the public wanting to know more!'

The publicity around these films provides a fantastic chance for Alzheimer associations around the world. A huge number of ADI members around the world have held events such as screenings of films for members of the public and this has given them the occasion to make known the work of their own association and the support available within their country as well as to call attention to what needs to be done by government to provide better care and provision for people with dementia and their carers.

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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 June 2008.

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■ Editorial



Orien Reid
Chairman, ADI

This latest edition of Global Perspective is full of exciting news and events from across the globe.

In this issue we focus on the evolution of international films chronicling the impact of dementia on individuals and families, a topic once hidden but today is out of the closet and on the big screen. We applaud the commitment and creativity of the film industry in helping to improve the lives of people with dementia through awareness and reducing stigma of dementia. Many of our members have taken the opportunity to raise awareness by holding screenings and events promoting the work of their association and calling for better dementia care and support around the world.

We also feature a group of people with dementia who are lending their support to World Alzheimer's Day 2008 and this year's focus on 'championing carers'. Three members of the UK's 'Living with Dementia' group share their experiences and describe the partnership they have with their carers. This year we continue with the popular theme of 'No time to lose' and come together through our events on World Alzheimer's Day to call on governments to give carers the recognition and support that they deserve!

■ Events

26 April 2008

Neurodegenerative Disease Research Open Day
London, UK
Tel: +44 20 7848 0550
Fax: +44 20 7848 0632
Email: alison.sharpe@iop.kcl.ac.uk
Web: <http://cnr.iop.kcl.ac.uk/events.aspx?entryId=118>

12 May 2008

Management of Common Problems in Older People
York, UK
Tel: +44 20 7290 2980
Fax: +44 20 7290 2989
Email: joyce.achampong@rsm.ac.uk
Web: www.rsm.ac.uk/academ/zye101.php

13 – 15 June 2008

11th Asia-Pacific Regional Meeting of Alzheimer's Disease International
Dementia Care: Fight and Light Taipei
Tel: +886 2 2701 8768 Ext. 203
Fax: +886 2 2702 2025
Email: alz2008@knaintl.com.tw
Web: www.alz2008.org.tw

29 – 30 April 2008

Satellite Congress of European Alzheimer's Disease Consortium (EADC)
Thessaloniki, Greece
Tel: +30 2310 810 411
Fax: +30 2310 925 802
Email: info@alzheimer-hellas.gr
Web: www.alzheimer-hellas.gr

12 – 14 May 2008

Alzheimer's Association 20th Annual Public Policy Forum
Washington, USA
Tel: +1 312 335 5833
Fax: +1 866 699 1235
Email: publicpolicyforum@alz.org
Web: www.alz.org/publicpolicyforum/08

26 – 31 July 2008

11th International Conference on Alzheimer's Disease and Related Disorders (ICAD)
Chicago, USA
Tel: +1 312 335 5790
Email: info@alz.org
Web: www.alz.org/icad

6 – 8 May 2008

1st International Conference: The Dementia Services Development Centre
Embracing the Challenge: Citizenship & Dementia
Belfast, Northern Ireland
Tel: +44 1786 467 740
Fax: +44 1786 466 846
Email: jemma.galbraith@stir.ac.uk
Web: www.dementiacentreni.org/conferences.asp

22 – 25 May 2008

18th Alzheimer Europe Conference
Breaking Barriers
Oslo, Norway
Tel: +47 231 200 42
Email: maija.juva@nasjonalforeningen.no
Web: www.alzheimer-conference2008.org

25 – 28 March 2009

24th Annual International Conference of Alzheimer's Disease International
Dementia: Engaging Societies Around the World
Singapore
Tel: +65 6379 5261/2
Fax: +65 6475 2077
Email: admin@adi2009.org
Web: www.adi2009.org



The importance of a diagnosis

By Elizabeth Nwoye, Nigeria

My mother is now 74 years old. I am not able to remember the exact date her problem began but it is about four years now. We noticed that she was becoming too forgetful. Many times she accused us of stealing her things but later we would see those items hidden somewhere. Our greatest fear was the day she went to church and could not find her way home.

It was very strange to all the children. We went to several hospitals in Lagos and the doctors told us that this was simply old age and nothing could be done about it. Later my mother would pass urine on herself without knowing and this was very distressing. One of our family doctors told us that my mother would require a surgical operation to correct the urine problem. We had to come down from Lagos to Anambra to find a doctor who would do the surgery because Anambra is our home state. Her condition continued to deteriorate such that eating was becoming very difficult. We then went to Psychiatric Hospital Nawfia where no satisfactory treatment was given. Instead her hand was always shaking too



Elizabeth's mother Uyaemes Roseline

much and she was getting very slowed down in all things.

Eventually we came to Nnamdi Azikiwe University Teaching Hospital Nnewi in 2006. For the first time we heard the word 'dementia' as the diagnosis. The doctor spent very long time with us and later sent us to the Alzheimer's Disease Association of Nigeria where we received many pamphlets, the most useful of which is Help for Caregivers. We felt so relieved just to realize that somebody is able to name the disease our mother

is suffering from. Before then my brothers who were not living with us were of the opinion that I might have caused this illness by not treating our mother well. Now we knew this was dementia and as the doctor told us we blame dementia rather than blame our mother or any one else for whatever abnormal behavior we see in her.

We started buying the medicines but they are very expensive. However, the treatment has been very helpful. The surgical operation was no longer needed. We were taught ways of handling the urine problem and even though mother still wets herself at times, we now know what to do and the problem has drastically reduced. It is very important to get an early diagnosis so as, first and foremost, to know what the actual problem is and then to start treatment early. The diagnosis has greatly helped us because proper treatment has stemmed further deterioration of the disease.

I think there are a lot of people with this disease but generally nobody knows what they are suffering from, and many doctors do not know what it is. I suggest that the public should be enlightened.

ADI announces new twins for 2008!

ADI is pleased to announce that this year's twinning partnerships are Brazil and Portugal, Sri Lanka and Scotland and Malta and The Netherlands. In the next few months we shall be helping the associations arrange their

first site visits and assisting with initial communications to help them to get the best out of their first few months. As the twins embark on their site visits they will get to know each other better and gain an understanding of the reality that the other association operates within. This is the time where they will

set their objectives and action plan for the next three years. Twinning will allow associations to work together on a project that interests them both and will provide benefits for both associations. ADI is grateful to the A & S Burton Charitable Trust for their support of the Twinning Programme.

Members' forum

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



CANADA

Alzheimer Society of Canada launches successful prevention campaign

During 2007, the Alzheimer Society of Canada (ASC) featured in their awareness campaigns the connection between a healthy body and a healthy brain. In January 2008 they took this message a step further, calling on all Canadians to make the commitment to better brain health by launching the Heads Up for Healthier Brains campaign, encouraging people to take charge of their brain health, in turn helping to reduce their risk of developing dementia.

During the 2008 campaign, more emphasis will be placed on the critical role that families play in maintaining a healthy lifestyle, and how people with the disease can maintain health and quality of life while coping with Alzheimer's disease.

ASC is helping provide both support and motivation to people through a variety of on-line incentives, including the launch of the 'Brain Booster', a new brain gym. The Society have also launched a contest with a national Canadian magazine that encourages people to make their commitment to better brain health, as well as enter their name into a draw for a chance to win some great prizes.

On January 30th, they capped off their Alzheimer Awareness Month and the launch of the campaign by co-hosting a reception on Parliament Hill. Along with the Speaker of the

House and a Member of Parliament from Halifax, they helped raise awareness about the dementia epidemic.

'We are asking politicians to do two things. First, we want them to make the commitment to improving their own brain health,' says Scott Dudgeon, Executive Director. 'Second, we want them to make the commitment to the thousands of their own constituents living with Alzheimer's and related diseases, by ensuring that dementia becomes a national health priority.'

To find out more you can go to www.alzheimer.ca where you can read members of the international dementia community pledging their healthy brain commitment including ADI's Executive Director and Vice Chairman.

WESTERN AUSTRALIA

Garden for people with dementia

Alzheimer's Australia WA has recently unveiled a new sensory water wall feature at a day care centre for people with dementia. The feature was added to a garden that has been specifically designed for people with dementia to enjoy the benefits of gardening and enjoying the surroundings that a garden provides. Wendy Hudson, Manager of respite services, said, 'Appropriate sensory stimulation can improve cognition because it helps people with dementia maintain an interest in their environment. Water provides a sense of movement and sound, creating a desire for people to venture out to the garden'.

Last year ADI staff had the privilege of visiting the garden based at the Mary Chester Centre in Shenton Park, Perth. The garden provides a variety of sensory experiences through growing different highly fragrant plants and a beautiful array of colorful flowers. The new water wall was created out of terracotta and blue tiles by members of the



Western Australia: Local students lending a helping hand to a Mary Chester Centre member in constructing the water feature

centre, along with staff, volunteers and students from a local college.

The water wall was first displayed at Alzheimer's Australia's conference last year in Perth where an ambitious sensory garden display was set up in the conference venue.

FRANCE

National Alzheimer plan for France

As a result of constant lobbying by Association France Alzheimer et Maladies Apparentées the President of France, Nicolas Sarkozy has recently announced a new 5 year plan for Alzheimer's disease from 2008-2012.

The 1.6 billion euro plan establishes a new Alzheimer's research foundation, measures to improve the quality of life for people with dementia both at home and in care homes, improved diagnosis and follow-up care and also measures to change people's attitudes to dementia and those who have it.

France Alzheimer welcomed the opportunity to participate in the numerous commissions set up to make proposals for the plan, most of which were amongst the measures announced by the President. France Alzheimer were particularly pleased that the plan places people with Alzheimer's disease and their carers at the centre of all decisions. Doctors have now been asked to also consider the health of the carer as well as the person with dementia and regional 'Alzheimer houses' are being established. Here, people with dementia and their families can find out about the information and help available to them. Local chapters of France Alzheimer will be present in these resource centres to help provide this support.

Over the next five years France Alzheimer will work to ensure that the 44 proposed measures of the plan are established and when France takes over the presidency of the European Union later in the year, Nicolas Sarkozy plans to make Alzheimer's



French President Nicolas Sarkozy announces dementia plan with Guy Le Rochais and Arlette Meyrieux, Vice President and President of France Alzheimer

disease a European priority, and improve European cooperation in the fight against the disease.

BAHRAIN

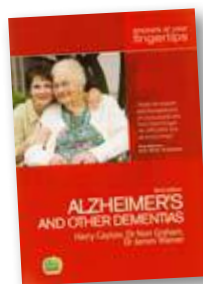
Bahrain association launches new support services

In April 2007 representatives from the Bahrain Alzheimer support group attended an Alzheimer University in London. They completed their three-day training by outlining their key objectives and highest on their list was a need to improve their information services for people with dementia and their carers. ADI are delighted to report that over the last 11 months they have experienced an exciting phase of growth! During the last year they successfully secured

funding to launch a national dementia package of support. The first stage involved volunteers setting up a much-needed helpline, providing one to one confidential help and support for people with dementia and their families. Following this achievement they also recently produced their first information booklet translated from materials supplied by Alzheimer Scotland.

In early February 2008 they took their next step and launched a website with the help of the Bahrain ministry of health. The website provides comprehensive information in Arabic informing the public on the different types of dementia and dementia care as well as promoting the group's mission, activities and support services. You can see the site at www.moh.gov.bh/alz

Finally, after months of campaigning by the Bahrain support group, the Bahrain ministry of health has just announced that it will be providing Reminyl (galantamine – a drug for people with mild to moderate Alzheimer's Disease) as the first dementia drug to be made available free of charge on the national health system. ADI congratulates the Bahrain Alzheimer support group in their hard work and dedication over the last year.



Alzheimer's and other Dementias – a revised edition

Alzheimer's and other Dementias: Answers at your Fingertips

A new edition of the book 'Alzheimer's and other Dementias: Answers at your Fingertips' has been released by Class publishing. This new fully revised edition gives detailed explanations about the different types and causes of dementia and updated information on the latest research into treatment and prevention. The book answers hundreds of real questions asked by people with dementia, their carers and family giving comprehensive and up-to-date information from authors Harry Cayton, Dr Nori Graham and Dr James Warner. To find out more or to purchase a copy of the new edition go to www.class.co.uk.

■ Living with dementia

People with dementia in the UK support the focus for World Alzheimer's Day 2008!

Last year on World Alzheimer's Day, we focused on people living with dementia and the role they play in our societies and Alzheimer associations. This year we draw attention to the carers and loved ones who are also living with and experiencing the disease through the partnership with the person they are caring for.

The Alzheimer's Society (England, Wales and N. Ireland) and members of their Living with Dementia team have been speaking out on the importance of directing our focus to carers by celebrating the contribution their carer makes and by giving them the recognition they deserve!

The 'Living with Dementia team' is a national programme set up by the Alzheimer's Society and is made up of people with dementia living in the UK. They share their experiences and knowledge at public events, in the media, and ultimately raise the level of awareness of dementia at a local and national level.

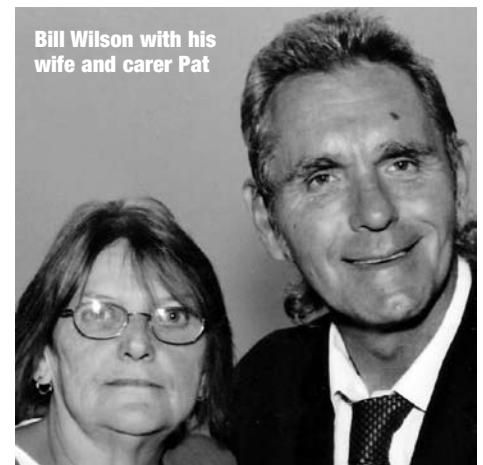
Ken Clasper ◉ As a person who has dementia with Lewy bodies, I know that at times I rely on my wife Janice for her support and help. As my carer she is the one person who I can rely on when times are difficult and although that does not happen very much at present, I do realise that in the future her role will become more and more difficult.

I do think a carer plays a very important role in this illness and this is a role which is unpaid and untrained for which makes it all the more difficult to think about.

I also feel that the carer has a real bond with the person they are looking after and that is something that is rare these days. ◉

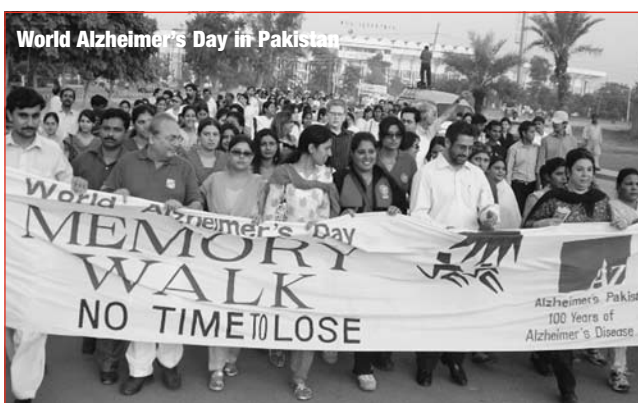
Bill Wilson ◉ My carer Pat is my wife, she also is my 'verbal punch bag' if anything goes wrong initially I blame myself because of my 'hosting' dementia, but swiftly it changes to Pat because she should be monitoring my actions – it is called passing the buck!

Fortunately Pat recognises the signs and always ignores my berating, I guess it must hurt but there are never any retorts from her. Standing back I realise she is suffering in silence, but do not all carers suffer also? Of course they do – it is when we are having better moments that we realise just how difficult their lives can become. ◉



Bill Wilson with his wife and carer Pat

Beric Morley ◉ I am fortunate to have a loving, caring wife who is unusually equipped by her background and education to support me. I have been frustrated to be dependent because of the solid basis of our marriage of over forty years. After the shock of early diagnosis when I was sixty, we tried to approach life in a positive way. We felt that we could be useful as a couple by helping others at our local Alzheimer's groups come to terms with their diagnosis. I am conscious that my needs have a direct impact on what my wife is able to do independently. I want to ensure that she has a fair share of our life together rather than her time being overtaken by my illness. To this end, I limit myself to things within my capability. Not only do I avoid frustration, but I also need less help from my wife. ◉



The theme for World Alzheimer's Day 2008 on 21 September is 'No time to lose'. ADI is encouraging its member associations around the world to focus on the realities of life with dementia for the person with the diagnosis and their carers. There are an estimated 24 million people around the world who have dementia, but there are millions more loved ones and carers who live with the daily challenges faced with coping with this disease. Join our World Alzheimer's Day campaign, speak out and together we can help fight for a better future.

■ Research update

Contribution of people with dementia to clinical trials

Marc Wortmann, Executive Director

Estimates of the number of drug treatments for Alzheimer's disease in the pipeline vary from approximately 50 to 140. Only a fraction of these drugs will eventually be approved by leading authorities such as the FDA (Food and Drug Administration) in the USA or EMEA (European Medicines Agency) in Europe. Before a drug is approved it must be trialled on volunteers and with so many trials taking place around the world I became curious about the process. I attended sessions during conferences and asked knowledgeable people and found that a lot of people with dementia are contributing to solutions for future generations.

At the moment there are two types of treatments for Alzheimer's. The first type is the cholinesterase inhibitor, which prevents the breaking down of acetylcholine, a neurotransmitter. The other one regulates glutamate, as excessive glutamate may lead to brain cell death.

To develop a new drug is a long process that may take 15 years from the first idea to becoming approved and then available. In the first stage a compound is developed in labs and, if it looks interesting, preclinical tests are done, mainly with mice. The problem with Alzheimer's disease is that to understand it, you have to understand what happens in the brain and we still do not know everything. When drug companies think they have a potential treatment, they start clinical trials. In the first phase, with 20-100 volunteers with healthy brains, the safety and dosage are evaluated. The second phase is conducted in people with a diagnosis

of dementia, also in small numbers (100-300), looking at efficacy and again safety. After this, phase three is large multi-centre studies that need to be conducted with 1000 or more people. These are the studies that are eventually reviewed by the FDA and EMEA, before a drug is released onto the market and can then be available for prescription. I talked to two representatives from drug companies about current trials.

One company, Myriad, started a trial for tarenflurbil with 1684 people with dementia in the USA and Canada and 840 in 10 European countries. The people with dementia in the early stages were recruited through memory clinics. They have to have already been on a stable dose of a current treatment for at least six months. Half of these people receive the real drug, while the other half are taking a placebo. Not everyone participates until the end of this 18 month trial. There are many reasons for this, including participants having to receive treatment for other unrelated diseases. It is interesting to note that participants in Europe are less easy to find, but generally continue with the trial for a longer period, probably because they are more loyal to their physicians. After the 18 month period, participants can start an 'open label' study and continue to receive those drugs for free until the drug is available in their country.

Two other companies, Elan and Wyeth, have been working since



the 1990s on the development of immunotherapeutic ('vaccine') approaches to Alzheimer's disease, including bapineuzumab. Elan and Wyeth began clinical studies in late 2003, eventually culminating in the initiation of a phase three clinical trial for bapineuzumab in late 2007 – the North American components of the programme are active, and the components in Europe and the rest of the world are expected to begin shortly. The phase three clinical programme is expected to involve approximately 4000 people with dementia worldwide. Each person's participation is expected to last 18 months. Participants are recruited by expert physicians and clinical investigators around the world. The companies post information on their studies to www.clinicaltrials.gov, a database of open clinical studies maintained by the National Institute of Health in the USA. The role of the carer in the trials is also important; the phase three programme requires that a carer is able to attend all clinical visits with the person with dementia. The carer will also help study investigators to evaluate the participant's symptoms.

I think it is remarkable that so many people with dementia contribute to drug trials and make a difference, in the hope that a breakthrough will help others in the future. Every study is important and, as a dementia community, we need to stay positive that a treatment and cure is within our reach.

For further information on drug trials around the world, please see:
www.emea.europa.eu/Patients/introduction.htm (Trials in Europe)
www.clinicaltrials.gov (Trials in the USA)
www.alz.org/alzheimers_disease_clinical_trials_index.asp

Dementia hits the big screen

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These events can also serve as fantastic fundraising opportunities!

The Alzheimer's Association in the US recently produced a toolkit, made available on their website, which enabled members to hold Oscars parties to spread awareness and raise funds for Alzheimer's around the evening of the Academy Awards (Oscars), at which *Away from her* was nominated for two of them.

The Los Angeles chapter of the association gave interviews to the press and sent messages to the film studios that produced the film in the hope that, if successful, those that were involved would mention the association and highlight dementia statistics.

Last year ADI had an opportunity to speak to a large audience at a Japanese film festival in London on behalf of Alzheimer's Association Japan (AAJ) following the release of the Japanese film *Ashita no Kioku (Memories of Tomorrow)*. We highlighted the work of ADI and AAJ as well as the main problems that are faced by people with dementia and their carers in Japan and what could be done to help make the situation better.

CEAFA, the Alzheimer association in Spain, was able to directly collaborate with the release of the popular film *¿Y tú quién eres?* so that it coincided with World Alzheimer's Day 2007. With the participation of Her Majesty The Queen Sofía of Spain they held a premiere screening, which attracted enormous attention from the media. The film is now being used as a video-forum by CEAFA in order to spread knowledge about dementia throughout Spanish-speaking countries.

Many associations are distributing these films as part



Members of CEAFA, the Alzheimer association in Spain, using the film *¿Y tú quién eres?* to promote World Alzheimer's Day 2007

of their information services and finding that the general public responds very well to this familiar medium. *Ex Memoria* is a film that has been developed with the Bradford Dementia Group in the UK, internationally known for their research into dementia care. The film has been distributed to hundreds of care workers, residential home managers, charities and specialists in the field, in the UK and beyond, as part of a Wellcome Trust scheme. The plot is based on a day in the life of Eva who, while in her later years in a care home, takes the audience back and forth through

the memories of her past and into the present. Writer and Director Josh Appignanesi said 'It hurls the audience into the confusion of a direct encounter with what a person with Alzheimer's goes through moment-by-moment. It's not supposed to give easy answers, but to stimulate real thought about an individual's biography and how it subtly comes into play in their present needs. If the film enhances a greater sensitivity, then that's a huge victory.'

In a world where a new case of dementia develops every seven seconds and an estimated 24 million people are living with dementia today, it was only a matter of time before we started to see stories of this disease and its devastating effects being portrayed in the mainstream media. Now is the time to build on this momentum and bring this disease out of the shadows by harnessing public awareness and calling for action from governments around the world to provide the necessary services and vital support for now and the future.

Future conference update

ADI does not have a conference in 2008. We are currently working hard preparing our conferences for 2009 and 2010.

ADI will hold its 24th International Conference in Singapore, 25-28 March 2009. We are excited to be organising a programme that reflects the conference theme 'Dementia: Engaging Societies Around the World' and have some exciting plenary sessions lined up.

You can register your interest in the conference and get the latest news at www.adi2009.org. During the 2009 conference ADI will celebrate its 25th anniversary, so be sure to put the date in your diary!

ADI's 25th International Conference in March 2010 will be held in the coastal city of Thessaloniki in Greece. The venues have now been selected and the first stages of the development of the scientific programme have begun. We look forward to welcoming delegates from around the world and experiencing the Greek hospitality for which they are famous.