

ADI's 21st annual conference • Regional symposium on Alzheimer's disease and related disorders in the Middle East

Putting dementia on the map in Turkey and the Middle East

'We are proud that we will be the hosts of ADI's first meeting to be held in this part of the world' Prof Murat Emre, Chairman, Turkish Alzheimer's Society

Alzheimer's Disease International (ADI) and the Turkish Alzheimer's Society (TAS) are excited to be organising 'Bridge at the Crossroads', the 21st annual international conference of ADI. Taking place in Istanbul, Turkey from 28 September to 1 October the event will bring 2000 people from all cultures and disciplines together. The conference aims to raise essential awareness about dementia in Turkey and the Middle East and foster regional and global networking and collaboration.

TAS was established in 1997 and is now one of the fastest growing civil organisations in Turkey. Turkey's population is 71,000,000. A recent study in Istanbul revealed that the prevalence rate of Alzheimer's disease for people above the age of 70 is 10%. It is estimated that there are 250,000 people with Alzheimer's disease in the country.

As Turkey's population gradually ages TAS recognises that dementia will become a significant issue for all of society as the burden of care shifts away from families to care

The Turkish Alzheimer's Society celebrate World Alzheimer's Day 2004



professionals. Current priorities for TAS are:

- Extend their network of six chapters
- Open more day care centres
- Raise awareness amongst professionals and family members so that memory loss is no longer seen as a natural consequence of aging.

Hosting the conference will enable TAS to achieve these aims through raising awareness about dementia and encouraging caregivers to become involved in the society's activities.

'Reaching out to people in the Middle East is our priority for 2005' Elizabeth Rimmer, Executive director, ADI

ADI is keen to foster new contacts and partnerships in the Middle East using Turkey's proximity to the region. Through ADI's Istanbul conference and the satellite symposium on Alzheimer's disease in the Middle East, ADI will encourage the region to join the global movement to put dementia high on the international health agenda. Alzheimer's Association Lebanon (AAL), one of ADI's newest members, is hosting the Arab conference on Alzheimer's disease from 3 to 4 March. ADI attendance at this event will further the shared goal of promoting the establishment of new Alzheimer associations in the region.

AAL hopes that its event will raise regional awareness about dementia and help achieve the aim of opening the first

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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 **31 May 2005**.

NEW ADDRESS

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Elizabeth Rimmer
Executive Director

Editorial

I wrote this surrounded by crates and packing materials, as we were about to move office the next day! For 20 years our office space has been generously donated, first by the Alzheimer's Association USA and then by the Alzheimer's Society UK. Moving to our own premises is an exciting new step forward, of which we have several planned for this year. These include: the development of our twinning/buddying programme to encourage skill exchange and learning between ADI members; the Asia Pacific regional Alzheimer University on advocacy and organisational development; and our first conference in the Eastern Mediterranean region. We have ambitious plans for World Alzheimer's Day, when we will launch updated global prevalence figures. And we are working more closely with Alzheimer Europe.

In preparation for the move I went through some of the old files. It has been motivating to feel the excitement and enthusiasm in the early correspondence as the mission of ADI was developed. That excitement and enthusiasm is still here today as we continue to extend our reach and work towards gaining better recognition of the needs of people with dementia and their families throughout the world.

Announcements and conferences

2005

11-13 May
Alzheimer's Australia National Conference
Living with Dementia – Positive Solutions
Sydney, Australia
Email: krennie@alznsw.asn.au
Web: www.alzheimers.org.au

8-12 June
2nd Congress of the International Society for Vascular Behavioural and Cognitive Disorders
Florence, Italy
Tel: +39 055 456531
Fax: +39 055 4565440
Email: info@regiacongressi.it

9-12 June
15th Alzheimer Europe Conference
Dementia Matters
Killarney, Ireland
Tel: +353 1 622 0125
Fax: +353 1 662 0126
Email: info@conferenceorganisers.ie
Web: www.alzheimer-conference.org

18-21 June
Alzheimer's Association International Conference on Prevention of Dementia
Early diagnosis and intervention
Washington D.C., USA
Tel: +1 312 335 5790
Email: info@alz.org
Web: www.alz.org

27-29 June
International Association of Homes & Services for the Ageing
Creative Solutions for an Ageing Society: Sharing the Wisdom
Trondheim, Norway
Email: iahsa@aahsa.org
Web: www.aahsa.org/iahsa/iahsaonline/Proposal

23-24 July
Alzheimer's New Zealand National Conference
Quality of Life for Those with Dementia
Wellington, New Zealand
Tel: +64 4 381 2362
Fax: +64 4 381 2365
Email: nationaloffice@alzheimers.org.nz

26-29 July
13th Annual Alzheimer's Association Dementia Care Conference
Chicago, USA
Tel: +1 312 335 5790
Email: careconference@alz.org
Web: www.alz.org

14-19 August
12th International Psychogeriatric Association Congress
Aging with Dignity
Stockholm, Sweden
Email: ipa@ipa-online.org
Web: www.ipa-online.org

1-2 October
Regional Symposium on Alzheimer's Disease and Related Disorders in the Middle East
Istanbul, Turkey
Tel: +90 212 533 8575
Fax: +90 212 533 4393
Email: muratemre@superonline.com
Web: www.worldeventsforum.com/alz.htm

28 September – 1 October
21st International Conference of Alzheimer's Disease International
Bridge at the Crossroads
Istanbul, Turkey
Tel: +90 216 467 06 47
Fax: +90 216 467 06 51
Email: congress@topkon.com
Web: www.adi2005.org

20-23 October
4th International Congress on Vascular Dementia
Porto, Portugal
Tel: +41 22 908 0488
Fax: +41 22 732 2850
Email: vascular@kenes.com
Web: www.kenes.com/vascular

5-13 November
18th World Congress of Neurology
Sydney, Australia
Web: www.wcn2005.com

17-20 November
2nd International Congress on Brain and Behaviour
Thessaloniki, Greece
Email: kfount@med.auth.gr
Web: www.psychiatry.gr

Visit www.alz.co.uk/events for more conference announcements



Carer's story

By Kwan Saw Hah, Malaysia

A new relationship with mum

Although my mum had no formal education, she was always an independent and capable woman. She used to have two jobs and did all her own banking. When she retired, she looked after my learning-disabled daughter, Michele, while I was at work.

The first signs of forgetful behaviour were small: the kettle would be left boiling or the tap left running. Sometimes she would accuse Michele of taking her things. At first I thought nothing of it and put it down to old age; she was in her late 70s.

Then things got a bit out of hand. She would forget to bring bits of her shopping home from the market and would insist on taking the bus back to pick them up. Around this time, I read an article in the newspaper about Alzheimer's disease and suspected that mum had this illness.

After she was diagnosed with early stage dementia, I contacted the Alzheimer's Disease Foundation Malaysia support group, who were also mentioned in the article. Since then, I have taken mum and Michele with me to the group's monthly meetings many times. It has been a great balm for my rather tested nerves! I regularly unload my caregiving stress with the other members of the group.

Caring for mum is not that difficult. She is the gentle type, hardly raises her voice and doesn't grumble at all. Interestingly, mum's occupational therapy is playing solitaire and she's still quite good at it, except for the occasional slip-up. Mum also plays 3-kaki mahjong once in a while. When she is playing her games, she is focused. I know she is kept well occupied and safe, so I do not worry about her. This gives me time and peace of mind to do the housework, send Michele to and from her training centre, and even enjoy some quiet leisure moments just for myself.

What I'm not happy about is the lack of support from my siblings. I am one of five children. In the initial period after diagnosis, I would get weekends off when mum would go and stay with them. Lately, as I've grown weary of voicing my needs to them, this no longer happens. However, my elder sister, who lives in Brunei, has been a great, if distant, support. For Christmas 2003, she gave me, mum and Michele an all-expenses-paid holiday in Perth, Australia. We truly enjoyed ourselves then!

I've been longing to go back to work and get back a sense of independence and self esteem; to be a 'productive' citizen. I am still unable to do so as there is no one to take care of mum and I know she would not be comfortable with a maid. I also



Kwan Saw Hah and her mum Mdm Ho Geok Eng

miss travelling by myself, a pursuit that I enjoy tremendously.

I have been caring for my mum for four years now. Despite feeling very alone in this journey, I'm thankful for the occasional breaks and the warm friendship I get from the support group. I'm also grateful to my elder sister for the lovely 'rewards' she has given us.

However, most of all, I'm truly glad to have developed a new relationship with my mum. We hug and hold hands a lot more now than we did before her illness. She was a working mum and used to be quite a strict disciplinarian. We were brought up to not be open about our love but now we are quite like friends and show our feelings through touch. It has allowed us to communicate on a new level and has been an excellent way of for us to bond.

Continued from front page

dementia care home in the country. These are challenges that are shared by the Iran Alzheimer Association (IAA), another new member of ADI. IAA have recently been successful in lobbying the Iranian government (see page 4) and hope to build on this in seeking government funding to organise a prevalence study.

The issues faced by these new ADI members demonstrate challenges

that are common worldwide.

These challenges, in addition to topics relevant to more established associations such as fundraising and organisational growth, will be discussed at ADI's 2005 conference. The global ADI network will share best practice to promote quality of life for people with dementia and their carers. Come and share your experiences, make new partnerships and join the ADI network!

21st International Conference of ADI
28 September – 1 October 2005
Istanbul, Turkey
www.adi2005.org
Abstract deadline: 1 April 2005

Regional Symposium on Alzheimer's Disease and Related Disorders in the Middle East
1 – 2 October 2005
Istanbul, Turkey
www.worldeventsforum.com/alz.htm

Members' forum

ADVOCACY SUCCESSES



The staff of the Iran Alzheimer Association

● IRAN Access to dementia treatment and interest-free loans

Over two years of campaigning by the Iran Alzheimer Association (IAA) has resulted in success. Health insurance in Iran now includes the provision of an anti dementia drug free of charge. IAA lobbied the government through a series of letters and meetings. Persuading the planning department to allocate funding for the change was a drawn-out process but ultimately worthwhile. With 70-75% of Iran's population covered by the health insurance scheme, this change could make a real difference to the lives of people with dementia.

Furthermore, IAA has worked hard to develop interest-free loans for the families of people with dementia. Benefiting three families each month, the loan of 3,000,000 Rials (US\$380) will not have to be paid back for three years. PR Co-ordinator Faraneh Farin commented, 'We are proud of what we have achieved. These are exciting times for our association – it is great to see our hard work pay off, making a tangible difference to the lives of people with dementia in Iran'.

● SCOTLAND

Working group makes bold recommendations

Alzheimer Scotland – Action on Dementia has worked with the Scottish Executive to produce a report and template that outline how dementia care services can be improved in Scotland. 'Overcoming obstacles' and the 'Template for Dementia Services' consider the problems of funding, awareness, diagnosis and stigma as well as providing a blueprint for change. The documents will be circulated throughout the Scottish health system. Jim Jackson, Chief Executive of Alzheimer Scotland said, 'The report and template will give an impetus to



From L to R: Bailie John Gray (representing Lord Provost of Scotland), Julie Miller and Jim Jackson of Alzheimer Scotland and Rhona Brankin, Deputy Minister for Health and Community Care in Scotland at the opening of a new dementia centre in Glasgow

the creation of dementia services fit for the 21st century'.

To read the report, visit: www.alzscot.org/media/shortlifewg.pdf

● THE NETHERLANDS

Successful parliamentary lobby and TV appearance



Marc Wortmann, Executive Director of Alzheimer Nederland

Dementia was discussed in the Dutch parliament for the first time in February. Alzheimer Nederland was amongst the organisations that provided expertise and support for these discussions. As a result, a programme to improve the quality of care for people with dementia, at home and in residential care, was approved by parliament. A manual has been produced that identifies common issues in dementia care and provides suggestions for how to overcome these. This document will be issued to regional partners in the field to promote good practice nationwide.

Alzheimer Nederland are pleased that dementia is finally on the political agenda and that they were part of the consultation process. In addition, Executive Director Marc Wortmann appeared on national TV to talk about the programme and the subject of dementia. He stressed the importance of a strategy for the future, 'both politicians and the public were reminded ... that the number of people with dementia will only increase and the time to act is now'.

● ISRAEL

Improving Quality of Life award

Congratulations to the Alzheimer's Association of Israel (AAI) who have been awarded the prize for 'Improving Quality of Life' by the Israeli parliament. The parliament will also produce a pamphlet about the work of AAI and why they were chosen above 130 other organisations to receive the award.

In addition, AAI will receive US\$10,000 to continue the vital work of their 35 branches throughout the country. Ruth Goldberg, AAI Chairman said, 'we are honoured to win the award. I hope that receiving it will increase public awareness, that more people will seek help and more professionals will find our association useful.'

● ZIMBABWE

Empowering doctors to diagnose

Zimbabwe Alzheimer's and Related Disorders Association (ZARDA) have taken crucial action to help raise doctors' awareness about dementia, where just one qualified neurologist exists for the whole country. Through ZARDA's hard work dementia has now been incorporated into the medical profession's continuing educational credit system. In order to keep their licences, doctors must regularly attend a certain number of presentations on various medical conditions. The new sessions on dementia are designed to empower doctors to screen for dementia and raise awareness about ZARDA and the services they provide.

ZARDA adopted the strategy in response to complaints that doctors were losing their objectivity and to the growing number of people with AIDS-related dementia not seeking help. So far the results have been good; doctors who formerly did not diagnose dementia have begun to do so and the number of referrals has increased.

● SPAIN

2004 – a year to celebrate

Confederación Española de Familiares de Enfermos de Alzheimer (CEAFA) heralded 2004 as their most successful year yet. Their first national conference was held at the end of October and attracted more than 500 delegates. Families, national and regional authorities and professionals exchanged knowledge and ideas at the two-day event. Furthermore, the Queen of Spain attended the opening of a new complex for people with dementia in Madrid. Communications officer Silvia Balanza commented '2004 has been a great year for CEAFA and we hope to build on this in



CEAFA President, M^a Ángeles Díaz, with Conference Director, Emilio Marmaneu, at the 2004 conference

the coming 12 months, especially because 2005 is our fifteenth anniversary.'

● AUSTRALIA

Alzheimer's Australia Victoria support for Sri Lanka following tsunami



Mr Jude Perera, the ALP member for Cranbourne, Australia, receives a certificate from Lynette Moore, Executive Director of Alzheimer's Australia Victoria, detailing the donation from Alzheimer's Australia Vic to the Alzheimer's and Related Disorders Foundation of Lanka

Alzheimer's Australia Victoria has donated \$5,000 to the Alzheimer's and Related Disorders Foundation of Lanka in the wake of the Asian tsunami. The branch made the generous donation

following a meeting with their local member of Parliament, Mr Jude Perera who has a Sri Lankan family background and first hand experience of dementia. Lynette Moore, Executive Director for Alzheimer's Australia Victoria, explained, 'We wanted to help people affected by the double devastation of dementia and the tsunami'.

Tami Tamitegama, President of the Sri Lankan organisation, explained, 'we are very grateful for this spontaneous gesture of support. The tsunami has exposed the raw reality of service deficits for the community at large, but specifically for elders, who are heavily marginalised segment of the population.' Many fear that, with relief efforts focused on the direct effects of the disaster, donations to services provided by the Alzheimer's and Related Disorders Foundation of Lanka will suffer. Tami commented, 'The cold reality is that our donor community will not respond to an appeal [for dementia services] for some years to come.'

Engaging the public in the science of dementia

London's Institute of Psychiatry (IoP) held an Alzheimer's Disease Research Open Day in November last year. The day was organised by Prof Simon Lovestone, a member of ADI's Medical and Scientific Advisory Panel, and succeeded in raising community awareness and providing a deeper understanding of the scientific process.

ADI staff joined 150 people from across the UK to learn about topics such as the health effects of care giving, the genetic link in early onset Alzheimer's disease and the work of the 10/66 Dementia Research Group. Participants were also treated to intimate sessions with researchers in their laboratories in a truly behind the scenes tour.

'I wanted to present an exciting aspect of my work and to stress the importance of our research ... in a fun and interactive way. Maggot races were the answer!' Fiona Kerr, PhD student, IoP

In an inventive presentation, fruit fly maggots were used to demonstrate the effect of the tau and beta amyloid proteins in Alzheimer's disease. Genetically modified maggots were raced against normal maggots and the tau maggots were consistently slower.

Many participants were encouraged to learn that so much research is being carried out and will continue into the future, in order to provide better care and treatment for people with dementia.



PhD student Fiona Kerr checks the contestants in the maggot race

'We all really enjoyed it. Our students got a huge amount from the stimulating and intelligent members of the public that came'

Prof Simon Lovestone, IoP

If you would like to read more about the open day you can do so online at: www.iop.kcl.ac.uk/iopweb/blob/downloads/locator/locator-440-Alzheimeropenday04.pdf

■ Research update

Smell test may predict Alzheimer's

A five-minute odour identification test could eventually help to identify people with mild cognitive impairment that are likely to progress to having Alzheimer's disease. Findings on the study, led by Dr Davangere P Devanand, were presented in December at the American College of Neuropsychopharmacology annual meeting in San Juan, Puerto Rico.

The prospective study, which enrolled 213 elderly patients, showed that individuals with some cognitive impairment who are unable to identify 10 particular odours, including lilac, lemons, leather, pineapple and strawberry, are more likely to develop Alzheimer's disease than are people who can identify the smells.

If confirmed by further research, the test may be useful to physicians.

Dr Steven DeKosky, chairman of ADI's medical and scientific panel, commented, 'a simple, easy and inexpensive way to identify people for

closer observation or early intervention could be a significant aid to research, especially in large research studies.' www.pslgroup.com/dg/2488d6.htm

Early test for Alzheimer's

New research published in the Proceedings of the National Academy of Sciences suggests that it may be possible to diagnose Alzheimer's disease before symptoms start to appear.

Researchers used a new ultrasensitive 'bio-barcode' technique to measure the quantity of a potential marker for Alzheimer's disease known as ADDLs (amyloid-beta-derived diffusible ligands) in the spinal fluid of 30 people. The concentrations of ADDL for the people diagnosed with Alzheimer's disease were consistently higher than the levels in people that did not have a diagnosis of Alzheimer's.

Dr DeKosky said of the research, 'Although a very early finding, a great increase in sensitivity to detect the abnormal proteins of Alzheimer's disease would be helpful in identifying people for preventive studies or early

intervention. This is also applicable to detection of low levels of abnormal proteins in other neurodegenerative disorders.'

www.pnas.org/cgi/content/abstract/102/7/2273

Cancer drug may help

Also published in Proceedings of the National Academy of Sciences are findings about the effect on mice of a drug used to treat cancer. The drug paclitaxel (commercially known as Paxceed) was shown to have a positive effect on transgenic mice (mentioned in our December 2004 research update) with symptoms similar to Alzheimer's disease.

The drug works by binding to and stabilising structures inside brain cells called microtubules. These structures are important for communication between brain cells.

Dr DeKosky commented, 'Disruption of normal microtubular function occurs in AD. This study suggests another strategy, complementary to other therapeutic approaches, that may help to slow the progression of the pathological changes.'

www.pnas.org/cgi/content/abstract/102/1/227

■ Living with dementia

People with dementia communicating across the world

We are a small group of people with dementia living in the West Kent area of the United Kingdom.

In 2000, we began meeting weekly to write a website about our experiences and ways in which we live with dementia. Within our website we look at certain issues, an example of this is 'Things that help'. Contributions from those with dementia have included 'doing things with other people is encouraging, it helps to alleviate the danger of isolation', 'living day by day, moment by moment' and 'having things to look forward to'.

Our aims are to share personal experiences and common problems, to exchange views and to learn from each other. We believe that communicating in this way can minimise feelings of isolation, reduce the burden of problems when they are shared, give participants a role and enable them to focus on helping others and work together towards a common goal.

Alzheimer's disease and other forms of dementia will soon be affecting those generations who have lived and worked in the modern electronic communication world. Therefore, we feel that utilising such communication tools will become more and more relevant for sufferers in the future. With this in mind we would like to expand our activities by inviting other sufferers to join with us in establishing regular email contact and making contributions to our website. We would welcome suggestions as to how to expand the website and make it as useful a resource as possible for those with problems in common with us.

We have support from our local branch of the Alzheimer's Society for technical aspects of putting our material onto the website. Perhaps other local support groups would be willing to establish their own projects to facilitate electronic communication with us by their members. Our weekly meetings are attended by a



Communicating across the world: the West Kent website

professional support worker at our local branch who facilitates the process.

We would welcome the establishment of new email links with individuals and groups – within or outside the UK. We would be fascinated to have the opportunity to communicate with others living in different countries. If anyone would like further information on how our group runs we would be delighted to provide it.

Perhaps we are being ambitious but what we would like to achieve is the heading on our website, 'People with dementia communicating across the world'.

We are also carrying out a small pilot project to examine whether the use of voice recognition software will enable those with limited keyboard ability or computer skills to be able to take part in electronic communication programmes such as ours.

Please visit our website at www.alzheimersforum.org and email Alan and John. We would be delighted to hear from you and also to receive input into the website.

This article was written by the West Kent Branch of the Alzheimer's Society, UK.

Trek raises £3000

Congratulations and many thanks to Louisa Elliot and Stephen Carless who returned home in November after driving 15,000 km from Holland to the Himalayas and raising £3000 for ADI.

Travelling in a 45-year-old Land Rover, the pair braved all weather conditions, technical hiccups and a tight budget to make their dream a reality. The route – through Europe, Turkey, Iran, Pakistan and India – allowed Stephen and Louisa to meet some of the ADI members that their sponsorship will benefit.

Stephen explained, 'Our time in Kerala, India, was a real high point of the trip. When we arrived, we were met by a huge group of volunteers, nurses, children – and an elephant! It was a real honour to lead their parade and be a part of all the events. I found the dedication and hard work of the people I met incredibly inspiring! After World Alzheimer's Day, people came up to us in the street saying that they had seen us in the newspaper. It was great to know that the event had made a difference; that more people became aware of the society because of it – and that we had been a part of that.'

Now back working nine to five, their



Stephen, Louisa, Yasmin Rasheed and Hussain Jafri of Alzheimer's Pakistan

expedition seems like a long time ago but Stephen and Louisa's once-in-a-lifetime trip has made a real difference to ADI.

To read more about their adventures, visit: www.holland2himalayas.co.uk

World Alzheimer's Day 2005

We can make a difference - challenging the stigma of dementia worldwide

You can make a difference to the lives of people with dementia by taking part in ADI's 2005 World Alzheimer's Day campaign. Join us on 21 September to demonstrate your solidarity with this global cause and tackle the stigma that surrounds dementia

Dementia presents one of the greatest health and social challenges of our time but it often goes unnoticed across the world. The 18 million people with dementia worldwide are commonly stigmatised. We want to go beyond the statistics and demonstrate that all members of the global community can play a part in improving the quality of life of people with dementia and their carers.

We want to encourage all members of society in all nations to speak up about their experience of dementia: from the family carer who provides 24 hour support, to the member of parliament who votes on health policies, to the policeman who finds a confused person in the supermarket. Demonstrating how we all can be affected by dementia

in some way, no matter how small, will challenge the myths that exist.

21 September is a catalyst for action. This is crucial as the number of people with dementia is set to double over the next twenty years. World Alzheimer's Day events can raise essential funds and awareness, which can help to:

- Promote awareness so that people understand the early symptoms of dementia and seek help
- Provide people with dementia and their families with accessible information and support
- Train care staff and develop skills of healthcare professionals to diagnose and manage dementia
- Engage policy makers to provide adequate resources for care and research, now and for the future
- Promote research to develop better treatments and understanding of the disease
- Educate communities to understand and accept people with dementia



Raising awareness on World Alzheimer's Day 2004, Asociación Lucha contra el Mal de Alzheimer, Argentina

Make a difference!

Taking part in an event for World Alzheimer's Day, whether it is a Memory Walk, tea day or seminar, will:

- **Be fun**
- **Raise awareness of dementia to help tackle stigma**
- **Support your Alzheimer association and raise awareness about their services**
- **Demonstrate your commitment to the worldwide effort**
- **Make a difference!**

'Our 2004 campaign was the best yet! Over 60 countries participated and we want to build on this success with "We can make a difference".' Elizabeth Rimmer, Executive director, ADI

Want to take part?

ADI will:

- **List online the global events that you can take part in**
- **Provide campaign materials for the general public and Alzheimer associations**
- **Launch a new section on the ADI website, 'the global impact of dementia', to provide statistics**
- **Feature case studies of how dementia affects all members of society online**
- **Write to every Minister of Health across the globe**
- **Take part in a Memory Walk**
- **Issue a press release on the day**

For more information contact your national Alzheimer association to find out what they are planning or visit: www.alz.co.uk/WAD