



Alzheimer's Disease  
International

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# Global Perspective

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

## Faces of dementia around the world

A basketball challenge in Pakistan, a Snoezelen room in South Africa and training for police officers in Turkey were just three of the activities organised around the world for World Alzheimer's Day 2011. With a focus on recognising the faces that represent dementia globally and the aim of raising awareness on a local and national level, Alzheimer associations, like-minded organisations and individuals hosted events on and around 21 September.

See pages 6 and 7 for news of the global activities on World Alzheimer's Day.



Some of the websites celebrating Faces of Dementia for World Alzheimer's Day



## Join us in London!

Just three months remain until our 27th International Conference taking place 7–10 March 2012 in London, UK (a London filled with anticipation of the Olympics).

The conference will bring together representatives from around the world, from medical professionals and researchers to people with dementia and carers, all with a common interest in dementia. The conference programme promises to be equally as diverse with a range of streams including research, care, and, for the first time ever, a stream of sessions led by people with dementia.

To take advantage of the early bird rate, please register by 13 January 2012. For more information or to register visit [www.adi2012.org](http://www.adi2012.org)



## 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 January 2012.

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## Editorial Marc Wortmann, Executive Director



The last few months have been an exciting time to be a part of the global dementia movement. It started with the launch of the World Alzheimer Report 2011 on the benefits of early diagnosis and intervention. A report on the launch event and great media coverage is included on the back page of this issue.

The second highlight was the United Nations high-level meeting on non-communicable diseases on 19 and 20 September 2011. This meeting of 193 countries, including many Heads of State, adopted unanimously a political declaration on the importance of these chronic diseases. After six months of heavy lobbying and with the support of a strong coalition of 11 NGOs, the declaration included a paragraph that recognises the importance of mental health in general and Alzheimer's disease specifically. We can build on this for future policy-making internationally and in every country of the world. With this declaration in hand, no government can ignore the issue of Alzheimer's disease and other dementias anymore!

The day after the Summit, we celebrated World Alzheimer's Day. The list of activities gets longer every year and you will find examples in this issue. We don't yet have the final numbers, but it would not surprise me if more than 1 million people took part in at least one World Alzheimer's Day activity this year.

Now we are heading towards the 27th ADI conference in London in March 2012, the Olympic year. Make sure that you register in time; it is going to be exciting! Why not consider arriving a few days early to take part in the pre-conference events or enjoy the city of London. We have received more abstracts this time than for any other ADI conference so far, so the programme is sure to be a busy one. We will also see a stronger involvement of people with dementia throughout the programme.

I wish you all happy holidays and look forward to seeing you in March 2012!

## Events

### 2012

11 – 13 January 2012  
**14th Asia Pacific Regional Meeting of ADI**  
Bangkok, Thailand  
Email: [mcpc.thailand@hotmail.com](mailto:mcpc.thailand@hotmail.com)  
Web: [www.azthaimeting.com](http://www.azthaimeting.com)

7 – 10 March 2012  
**27th Annual International Conference of Alzheimer's Disease International**  
London, UK  
Email: [adi2012@mci-group.com](mailto:adi2012@mci-group.com)  
Web: [www.adi2012.org](http://www.adi2012.org)

9 – 12 May 2012  
**12th International Stockholm/Springfield Symposium on Advances in Alzheimer Therapy**  
Stockholm, Sweden  
Email: [ahamilton@siumed.edu](mailto:ahamilton@siumed.edu)  
Web: [www.siumed.edu/cme/alzheimer](http://www.siumed.edu/cme/alzheimer)

14 – 19 July 2012  
**Alzheimer's Association International Conference 2012 (AAIC)**  
Vancouver, Canada  
Web: [www.alz.org/aaic/vancouver.asp](http://www.alz.org/aaic/vancouver.asp)

4 – 6 October 2012  
**22nd Alzheimer Europe Conference**  
Vienna, Austria  
Web: [www.alzheimer-europe.org/EN/Conferences](http://www.alzheimer-europe.org/EN/Conferences)

18 – 20 October 2012  
**VI Congreso Iberoamericano de Alzheimer**  
Santiago, Chile  
Web: [alzheimeriberoamerica.org](http://alzheimeriberoamerica.org)

26 – 28 October 2012  
**15th Asia Pacific Regional Meeting of ADI**  
Beijing, PR China



## Saluting courage

Nilanjana Maulik, ARDSI Calcutta, India

I first became interested in working for people with dementia many years ago as part of my MBA internship programme. At that time I did not realise that this would become my life's work. Fortunately it did, and I am privileged to know thousands of individuals and their families over the years who have courageously faced this illness. All of them have touched me.

But I would love to salute two incredible women, one a mother and the other her daughter, whose courage have inspired my life.

Their stories are not stories of fighting oppression and coming out courageous. Their stories prove that nothing can be more courageous than simply living life with passion even in the midst of crisis.

Both of these women have battled Alzheimer's disease.

Shefali Chaudhuri, the mother, is 93 and a demonstration of courage against all odds. In many ways her life began at 75 when she learned that her daughter had Alzheimer's.

However, she found a way to convey hope, optimism, reassurance, dignity and respect for her daughter as well as for all of us. I have known her for the past 13 years and seen her do the impossible care – 24 hours a day, 7 days a week, 365 days a year. I have seen her intense concern for her daughter and unstinting generosity with her time.

Despite the pervasive influence of Alzheimer's in her life, she struggled not to let the disease define her. Her caregiving made her realise that there are hundreds out there like her who need help and that there was a role she needed to perform

which could help others, whilst also giving meaning to her own life. So she found a way to continue, not to just live but to live a beautiful life, a meaningful life. She started ARDSI (Alzheimer's and Related Disorders Society of India) Calcutta chapter. She says she does not have a simple prescription that will help you or someone you love live life beyond illness. The best she could do is to tell the story of how she coped and tried, sometimes successfully, sometimes not, to rise above the illness.

Deepika, her daughter showed early signs of Alzheimer's in the fall of 1993 at the age of 51. She had faced life with a struggle early on. She had a polio attack at the age of 6, which meant she needed to undergo several operations. Despite the serious handicap that affected her ability to walk, she was undaunted, and participated in most activities with determination. Her adventurous spirit was notable, as despite the severe disability in one leg, she learned to drive a car, went to several international student exchange *Experiment in International Living* trips where she engaged directly in the new culture, community service, language study, theatre, arts, travel, ecology, cooking, photography, or outdoor adventure in the visiting countries, and made friends all over the world. She even went to support the war effort where she drove an ambulance as a volunteer in 1965. She married late but lost her husband after five years. Despite all of these setbacks she came out strong.

However, Alzheimer's took it all from her. She lost the ability to communicate or comprehend.



**Shefali Chaudhuri (pictured centre), founder of ARDSI Calcutta, has always been keen to engage people of all ages.**

She had to take early retirement in 1994, as her memory started failing. Later, other faculties were affected, and she finally reached the stage that made it essential for her to be cared for full time. Her strength and determination is a reflection of being the daughter of her mother, Shefali Chaudhuri.

Deepika is now no more. She fought Alzheimer's disease for 18 long years with her mother beside her all the time.

So, here we saw a lady who had the courage to take the risk of letting her daughter live at home until the end. By doing this she taught all of us a lesson that dying need not be a nightmare unless we make it one. For the daughter, anyone who has seen a person in peace and not in resignation will never forget her.

In my journey of life, I had the honour of sharing my space with people with dementia and caregivers who spend endless hours in pursuit of connection. These people have courage to look at themselves more objectively and they are able to put aside the unessential threads of life. They get to the bottom of issues and have the courage to look at things in painful but revealing ways.

To find out more about the work of ARDSI Calcutta visit [www.ardsikolkata.org](http://www.ardsikolkata.org) or email [ardsikolkata@yahoo.co.in](mailto:ardsikolkata@yahoo.co.in)



# Members' forum

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

## AUSTRALIA

### New BrainyApp launched



A world first brain health app, designed by Alzheimer's Australia and Bupa Health Foundation, was launched on 9 November and hit number one in the

Australian App Store, with 41,000 downloads, in just 48 hours.

BrainyApp, which may help people reduce their risk of Alzheimer's disease and other forms of dementia, has also gained success in the New Zealand App Store.

Glenn Rees, CEO of Alzheimer's Australia, said the rapid success

of BrainyApp demonstrates that Australians are eager for information and strategies to help them improve their brain health.

'It is fantastic to see that Australians want to make active lifestyle changes to reduce their risk of developing dementia.'

BrainyApp is currently available as a free download for users of iPhone, iPod and iPad devices. At the time of going to press, efforts to make this available worldwide and for a range of devices were almost complete.

*More information about BrainyApp is available at [www.brainyapp.com.au](http://www.brainyapp.com.au)*

## USA

### Alzheimer's from the frontlines

To support the USA's National Alzheimer's Plan and ensure public participation in the planning process, the Alzheimer's Association gathered input from Americans across the country on the leading issues that a National Alzheimer's Plan must address. The findings of this research have now been compiled to form the *Alzheimer's from the Frontlines* report.

Over 43,000 people across the country participated in the Association's public input process to share their insights, concerns and hardships. Ten key issues emerged that they believe the U.S. Secretary of Health and Human Services must address in the National Alzheimer's Plan, now being created through the implementation of the National Alzheimer's Project Act (NAPA):

- A lack of public awareness
- Insufficient research funding
- Difficulties with diagnosis
- Poor dementia care
- Inadequate treatments
- Specific challenges facing diverse communities
- Specific challenges facing those with younger-onset Alzheimer's
- Unprepared caregivers
- Ill-equipped communities
- Mounting costs

*For information on this campaign, and the creation and implementation of the National Alzheimer's Plan visit [www.alz.org/napa](http://www.alz.org/napa)*

## SRI LANKA

### Service centre open



**Frank Schaper, right, presents Tami and Lorraine Tamitegama with an award of achievement**

Following months of preparations and hard work the Lanka Alzheimer's Foundation's Service Centre in Colombo was declared open on World Alzheimer's Day, 21st September.

The traditional opening of the Centre was attended by a large gathering of friends, donors, people with dementia and family carers. Frank Schaper, Executive Director of Alzheimer's Australia WA, attended the opening on behalf of ADI following his many years of support for the Foundation since their incorporation in 2001.

In a speech during the opening, Tami Tamitegama, Founder of the Lanka Alzheimer's Foundation, gave thanks to all who had provided funding, expertise, advice, gifts and other contributions in the development of the Centre.

The Centre will provide a host of services, including respite care, a memory clinic, family counselling, and training for dementia carers. A special charity shop, 'Memories', will also be part of the Centre.

As a final remark at the opening of the Centre, Tami announced that he would shortly begin documenting the first ten years of the Lanka Alzheimer's Foundation's development, to enable friends and supporters to witness its growth.

*To find out more about the Centre and the work of the Lanka Alzheimer's Foundation visit [www.alzlanka.org](http://www.alzlanka.org)*



## SWITZERLAND

### InfoMobil on the road

With a converted caravan and an array of handouts and brochures, Association Alzheimer Suisse set out in March 2009 on a pilot project of their InfoMobil.

With the aims of giving a face to the association's local branches, raising awareness, and disseminating information, the project was a great success and, as a result, a national tour of the country took place in 2010. A team of more than 50 volunteers, dressed in white tops and pink shawls to match the association's branding, took part in the initial 26-day tour, reaching 12 locations including supermarkets, hospitals and smaller communities.

Thousands of leaflets were distributed during the tour and the association also took the opportunity to gather over 3,000 signatures of support for their *Priority Dementia* manifesto.

Results of the tour have been significant, with an increase in demand for the cantonal Alzheimer's counselling centres and frequent requests for cantonal representatives to speak at other health care and charitable organisation events. An increase in the flow of donations has also been noted following the tour.

Since the initial tour over 250 volunteers have taken part in disseminating information from

the InfoMobil and the success of the campaign has ensured its continuation, not just through 2011, but also into 2012.

*To find out more about the work of Association Alzheimer Suisse visit [www.alz.ch](http://www.alz.ch)*

## LATIN AMERICA

### V Congreso Iberoamericano sobre enfermedad de Alzheimer

SCUAL in Cuba played host to the V Congreso Iberoamericano sobre enfermedad de Alzheimer in October, bringing together those from across the Spanish-speaking world to share the latest developments in prevention and improved care for people with dementia.

Delegated gathered from 20 countries across Latin America, the Caribbean and further afield for a range of sessions, including round table discussions on genetic and environmental differences in dementia and caregiver programmes.

Members of the 10/66 Dementia Research Group provided a valuable workshop on how national Alzheimer associations could use the findings of the Group in their work.

The next meeting of Alzheimer Iberoamerica will take place in Montevideo, Uruguay in October 2012.

*For more information about the work of Alzheimer Iberoamerica visit [alzheimeriberoamerica.org](http://alzheimeriberoamerica.org)*

## Dementia newsflash

### Bulgaria

Compassion Alzheimer Bulgaria have recently begun a small art therapy and Alzheimer Café pilot project in Varna.

### Canada

Alzheimer Society of Canada have announced the appointment of a new CEO. Mr Naguib Gouda will begin work with the Society in December.

### Denmark

After a year of advocacy and lobbying efforts, Alzheimerforeningen were pleased to announce the adoption of the country's national dementia action plan.

### Ireland

The Alzheimer Society of Ireland have developed a dedicated website for their Memory Ribbon Tree this year, allowing individuals to share memories of those touched in some way by dementia.

### Peru

APEAD are working closely with volunteers and the media to approach politicians as part of a new campaign to promote dementia as an important cause during the recent changes in the country's government.

### Venezuela

Photographer, Leo Ramirez, was awarded second prize in ADI's photography competition in 2009. He has now developed a website in both Spanish and English, charting his grandmother's life with dementia. Visit [www.leoramirezphoto.com](http://www.leoramirezphoto.com)

# World Alzheimer's Day 2011



The opening of a new research centre in Scotland



An Alzheimer Café in Belgium



A wine-tasting fundraiser in Bermuda



A training session in Mexico



Memory Walk preparations in Trinidad and Tobago



A public information stand in Zimbabwe





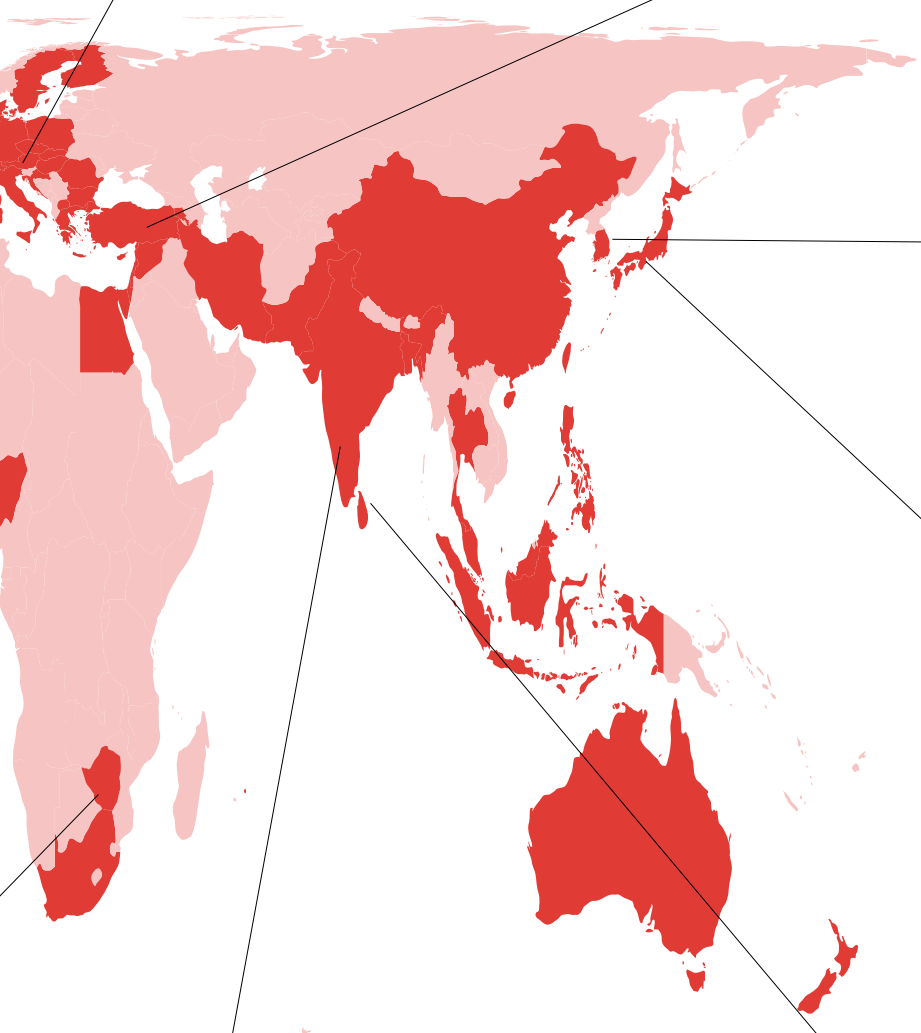
Over 65 countries marked World Alzheimer's Day this year. Here are just some of the activities that took place across the world. For a full report and details of World Alzheimer's Day activities visit [www.alz.co.uk/world-alzheimers-day](http://www.alz.co.uk/world-alzheimers-day)



A meeting of people with dementia in Macedonia



A cultural and sports event in Iran



Traditional dance entertainment in South Korea



Information dissemination in Japan



Awareness raising in Goa, India



A Memory Walk in Sri Lanka

MEMBERS' FORUM CONTINUED FROM PAGE 5

**ASIA PACIFIC****Conference rescheduled**

Due to the severe flooding in and around Bangkok, Thailand, the Asia Pacific regional meeting of ADI

could not take place in November and had to be postponed.

ARDA-Thailand has worked extremely hard to ensure that the conference can still go ahead and it has now been rescheduled for 11–13 January 2012.

We would like to wish ARDA-Thailand and conference delegates a very enjoyable and successful event.

*For more information about the conference visit [www.azthaimeting.com](http://www.azthaimeting.com)*

# The last taboo

Dementia, sexuality, intimacy and sexual behaviour in care homes

The need for affection, intimacy and relationships for people with dementia in care homes has too often been ignored and sidelined in policy and practice, according to a new guide by the International Longevity Centre, UK.

*The last taboo: A guide to dementia, sexuality, intimacy and sexual behaviour in care homes* provides care home workers and managers with information and practical advice about this complex, controversial and sensitive issue.

Sally-Marie Bamford, a senior researcher at the ILC-UK said, 'The onset of old age and dementia does not erase the need for affection, intimacy and/or relationships and yet this aspect of ageing creates confusion, fear and misunderstanding for many. We need to start to challenge some of the negative attitudes and misconceptions about older people with dementia and their sexuality and move to a more person-centred approach to dementia care.'

Alistair Burns, the National Clinical Director for Dementia for the UK, added: 'This report is an immensely valuable document which deals

with this most sensitive of issues in a clear and open way. It shines a light on this hitherto hidden aspect of dementia care. By discussing the subject openly the opportunity is there to promote good care, underscored by empathy. Intimacy is a need and improves wellbeing – yet mental capacity needs to be assessed and its lack not assumed.'



## The guide for care staff is summarised in ten key points:

- 1 Some residents with dementia will have sexual or sensual needs.**
- 2 Affection and intimacy contribute to overall health and wellbeing for residents.**
- 3 Some residents with dementia will have the capacity to make decisions about their needs.**
- 4 If an individual in care is not competent to decide, the home has a duty of care towards the individual to ensure they are protected from harm.**
- 5 There are no hard and fast rules. Assess each situation on an individual basis.**
- 6 Remember not everyone with dementia is heterosexual.**
- 7 Inappropriate sexual behaviour is not particularly common in dementia.**
- 8 Confront your own attitudes and behaviour towards older people and sex generally.**
- 9 Communicate – look at how you can improve communication with your colleagues, managers, residents and carers on this subject.**
- 10 Look after yourself and remember your own needs as a care professional.**

*To find out more about this report contact Sally-Marie Bamford at [sallymariebamford@ilcuk.org.uk](mailto:sallymariebamford@ilcuk.org.uk)*



## ■ Research update

# Antipsychotic drug use in the treatment of behavioural and psychological symptoms of dementia

Urs Mosimann and Irène Lustenberger

Department of Old Age Psychiatry  
University of Bern, Switzerland

**B**ehavioural and psychological symptoms of dementia (BPSD) develop in almost all people with dementia during the course of the disease. The prevalence of BPSD is highest in nursing homes where most residents (90%) experience them as dementia progresses. Many residents have different BPSD symptoms at different times. They include psychological symptoms, such as psychosis (disturbed thinking and visual hallucination) and mood disorders (mainly depression and anxiety).

BPSD also include behavioural symptoms such as physical or verbal aggression, wandering and inappropriate behaviours, which impair the quality of life of residents and caregivers. BPSD can contribute to depression in caregivers and is a common reason for nursing home admission.

### Multi-step approach

Treatment of BPSD is difficult. Recent recommendations suggest a multistep approach, starting with the analysis of the symptoms and addressing their potential causes. Common causes of BPSD are pain, urinary tract infection, chest infection, impaired hearing and impaired sight and the degree

of environmental stimulation (for example, low lighting and extreme noise).

### Non-pharmacological interventions

Treatment guidelines recommend the use of non-pharmacological interventions before medication is used. Non-pharmacological interventions include validation therapy, aromatherapy, multisensory stimulation, music therapy, massage and behavioural modifications. Validation therapy is a pragmatic approach and is based on the principles of providing empathy and respecting the individual's reality. The therapy involves elements of communication, reminiscence and activities such as music or movement. Successful non-pharmacological management of BPSD needs trained staff, person-centred care and more staff time with people.

### Pharmacological treatments

If non-pharmacological interventions are unable to alleviate BPSD, then pharmacological treatment may be considered. Different medications are available for the management of BPSD and a particular focus of research and public discussion



Urs Mosimann

in the past 5 to 10 years has been on the use of antipsychotic drugs. Antipsychotic drugs were introduced in the 1960s and 1970s for the treatment of schizophrenia and they are commonly used as an off-licence treatment for aggression and agitation in people with dementia. Since 2005, regulatory authorities (the US Food and Drug Administration and UK Medicines and Healthcare products Regulatory Agency) have issued warnings that off-licence prescribing of antipsychotics in people with dementia can be associated with an increased risk of stroke, with faster disease progression and with increased mortality. These warnings have reduced the prescription of antipsychotics in the US and elsewhere and will further influence clinical practice. But there are still further steps to go.

CONTINUED ON NEXT PAGE...

RESEARCH UPDATE CONTINUED FROM PAGE 9

## Psychotropic medication

Recent findings suggest that psychotropic medication in nursing homes is still too high. Lustenberger and colleagues (*Swiss Med Wkly*, 2011. 141: w13254) found that 71% of nursing home residents with dementia in Switzerland are taking psychotropic medication, most commonly antipsychotics and antidepressants.

Antipsychotics are mainly prescribed for the treatment of BPSD and 70% of the residents were taking them long term (for more than 6 months). Further, their use at entry predicted their use during follow-up. This practice will need to be reviewed carefully in view of recent treatment recommendations. They suggest that the use of antipsychotics should be restricted to clear target symptoms (that is, severe aggression and psychosis) and reviewed regularly (every 2-3

months). The evidence for long-term treatment with antipsychotics is poor and most trials addressing withdrawal of these drugs did not find relapse of symptoms when doing so.

## Differences between countries

There are differences in the prescription rates between countries. For example, antipsychotics are more commonly prescribed in Switzerland than in Northern America or China. It is likely that the availability of the drugs and guidelines are influencing prescription habits.

## Shortages of staff

However the use of medication may also be a result of staff shortage and the lack of trained staff in nursing homes, which are needed for non-pharmacological

treatment strategies. In many western countries staff recruitment is difficult and wages remain low. If the training of the nursing home staff is improved, jobs may become more attractive which may ease recruitment. Trained staff speaking the native language of nursing home residents, or who can address the needs of migrant nursing home residents, are a very valuable asset.

## National dementia strategies

National dementia strategies should therefore address the needs of residents, caregivers and health care professionals to improve standards of care and treatment in nursing homes. A joint approach will help to further improve the challenging management of BPSD in nursing homes.

## Living with dementia

### A message from Helga Rohra



Dear brothers and sisters touched by dementia!

We are permanently raising awareness. In my city, Munich, or across Germany I am often invited to talk about the impact of dementia on my life. My listeners are medical staff, carers, relatives or just people interested in the topic.

I point out the 'haves' and not the 'have nots' in our life. I speak up for being granted the same rights as all the other people with a disability. Germany has got a special way of ignoring social rights for people who have just the diagnosis of dementia and no other physical disability – it is a shame.

The best job I did talking about this was in a magazine with two million copies sold – wow!!!

In office hours, every Friday 11am to 12pm, I myself am counselling people who have a diagnosis of dementia or are experiencing the symptoms, even get the same medication – but have no diagnosis. It seems to be of great help to those who come. Even relatives show up.

My new book *Dementia – Stepping out of the shadow* will be a big step in raising awareness of dementia, especially showing people in the early stages and the challenges our societies have to face.

*Best, Helga Rohra  
Munich, Germany*

## ■ Living with dementia

# Is anybody listening?

## Can you hear me? Joan Uronis, USA

My name is Joan Uronis. I am 62 years old. I currently reside in Hudson, Ohio, USA. I am a long-time advocate for people with Alzheimer's disease. I have been involved with the Alzheimer's Association and am currently a co-facilitator for my local chapter in Hudson, Ohio.

I have a degree in Health Care Administration and have been in the health care field for over 20 years. More than half of those years were in executive positions. Throughout my career, I had the privilege of working with people with Alzheimer's and their families.

As the Executive Director of an Assisted Living Community, I often stepped out of my office to spend quality time with my Alzheimer's residents. It gave me joy and pleasure to sing with them, hug them and make them smile. It thrilled my heart to bring a smile to the face of a resident who had never smiled at the staff before. I felt as if I was somehow, in some way, connecting with them.

My mother, Mary Kalbrunner, spent the last year of her life in an assisted living community with Alzheimer's. Knowing she loved to sing I would sing *You Are My Sunshine* to her. It became our song. When I visited her in the assisted living, I would begin singing "our" song as soon as I saw her. Before I knew it, all the residents were joining in with smiles on their faces. My mother passed away in 2010 at the age of 92. I love her and miss her terribly.

At the age of 62, I was looking forward to embarking on the golden years of retirement with my husband, Al. We talked about travelling, spending time with family and friends

and "just enjoying life". Little did I know that retirement would come earlier than believed for me and possibly without all the hopes and dreams we had planned.

Working as a Hospice General Manager I began having memory problems. As time went on, I was falling more and more into forgetfulness making my job more difficult. I knew something was wrong but did not know what. I was terminated from my position in April 2011.

By July 2011, I was diagnosed with Younger/Early On-Set Alzheimer's, a rare form of the disease occurring in people under the age of 65. My neurologist informed me that I would no longer be able to work due to the worsening progression of the disease. Instead of letting the disease control me, I am controlling it. I consider my disease a gift and have accepted it with a positive attitude. It has given me purpose: to speak from the perspective of someone with the disease as well as for those who can no longer speak out on their behalf and their families.

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*'Advocacy is now my new career. It is my passion.'*

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As a person who enjoys working, Advocacy is now my new career. It is my passion. I will be a person who:

- Argues for our cause
- Speaks and pleads on our behalf
- Helps professionals better understand us
- Encourages professionals and leaders to give us a future we deserve by opening centres that offer care solely to us, once we are



**Joan, pictured with husband Al, was diagnosed with Alzheimer's disease after working in the field for 20 years**

no longer able to be properly cared for at home

- Pleads for specialised care centres where families will be able to sleep at night knowing their loved ones are safe
- Asks for us to be given the unique care we deserve, without neglect
- Requires centres where caregivers are certified and recertified in Alzheimer's care and the ratio of caregivers to patients is small enough to ensure quality care.

It is my hope to help society understand that Alzheimer's disease is not one to be ashamed of, hidden behind in silence or thought of as a mental illness. I am on a mission of giving Alzheimer's awareness the priority it deserves, the second most dreaded disease.

My mission may not come to fruition in my lifetime. My comfort will be in knowing that I have given it my all. I promise I will not go down without a fight. I will continue the fight as long as the disease allows me.

On behalf of us with Alzheimer's, thank you for listening and giving me the chance to be heard. I urge those with power, authority and the willingness to make the changes needed to step forward and take action in support of what is necessary to ensure us the future we deserve.





## World Alzheimer Report 2011

The launch of the World Alzheimer Report 2011 took place in New York, USA, on 13 September, with attendance from twenty-four organisations, including the Alzheimer's Association (US), the International Federation on Ageing and the US National Institute on Aging.

The event was presided over by Michael Hodin, Executive Director of the Global Coalition on Aging, with presentations from Martin Prince, the main author of the report, and ADI Executive Director, Marc Wortmann. Matthew Baumgart, Senior Director of Government Affairs at the Alzheimer's Association, was also present to highlight the impact of the report's findings on the USA.

Media coverage of the report appeared in more than 40 countries with a potential viewership of more than 200 million individuals. There was a 900% rise in media mentions of ADI in September compared to August, the majority of which were related to the report.

ADI would like to thank all members, organisations and individuals involved in the development and promotion of the report. We look forward to continuing to build upon this work with the next report in 2012.

For more information about the World Alzheimer Report visit [www.alz.co.uk/worldreport](http://www.alz.co.uk/worldreport)

**Michelle McGrath, former CEO of Alzheimer's Australia ACT, has stayed in the dementia field after her move to the USA last year**

## Honours for dementia advocates

Countless numbers of individuals around the world give huge amounts of their time to advancing the dementia cause and so it was a great pleasure to hear that two very important advocates in the field were recognised in the Queen's Birthday Honours List this year.

Former CEO of Alzheimer's Australia ACT, Michelle McGrath, has been awarded the Medal of the Order of Australia for her service to community health through Alzheimer's Australia in the Canberra region. Michelle volunteered as the Executive Director of Alzheimer's Australia ACT from 1997 to 2000, before being officially appointed to the position in 2001.

After more than ten years working with Alzheimer's Australia ACT, in July 2010 Michelle left Australia to move to the USA, but has continued to work on dementia projects and volunteers for the Alzheimer's Association Maryland Chapter.



Edward McLaughlin, former chair of the Scottish Dementia Working Group, received an MBE in the Queen's Birthday Honours List 2011. This award recognises Edward's ongoing work to raise awareness and demonstrate the many ways in which people can live well with dementia.

Edward was diagnosed with dementia ten years ago and has been actively involved with the Scottish Dementia Working Group since 2003. He played a key role in the development of the Charter of Rights for people with dementia and their carers in 2009 and has spoken out at numerous events both in Scotland and across the world.

ADI congratulate both Michelle and Edward on their success and hope they will continue their active participation in the dementia community.

**Season's greetings** ADI would like to wish all members, friends and associated organisations all the very best for the season and we look forward to continuing our work with you in the future.