

World Alzheimer's Day

21 SEPTEMBER 2005



Alzheimer's Disease
International



What is World Alzheimer's Day?

Every year on 21 September people from Australia to Zimbabwe take part in activities, from Memory Walks to seminars, to mark World Alzheimer's Day and show their global solidarity. World Alzheimer's Day is coordinated by Alzheimer's Disease International.

Observing World Alzheimer's Day:

- Encourages recognition of dementia
- Raises awareness
- Challenges stigma
- Engages policy makers.

We can all make a difference to the lives of people with dementia by taking part in Alzheimer's Disease International's 2005 World Alzheimer's Day campaign.

Join us on 21 September to show your support. We want to encourage all members of society in all nations to speak up about their experience of dementia. Demonstrating how we all can be affected by dementia in some way, no matter how small, will challenge the stigma that surrounds it.

Alzheimer's disease is the most common cause of dementia, a progressive degenerative brain disorder which affects memory, thinking, behaviour and emotion. Dementia knows no cultural or geographic boundaries and affects people worldwide.

Age is the greatest risk factor; about 5% of people over the age of 65 will develop dementia and about 20% over 80. Life expectancy is increasing worldwide and over the next 15 years the numbers of people with dementia will double. We need to take action now.

We want to challenge the barriers to dementia care, and encourage people with dementia and their families to come forward for the support available, so they do not face fear or embarrassment and hide the difficult issues they face.

Dementia presents one of the greatest health and social challenges of our time, yet it does not have the recognition it deserves.

By uniting on World Alzheimer's Day as a global community, we can show that there is much we can do together to improve the quality of life of people with dementia and their families.

Recognition of dementia

In most parts of the world dementia is still thought to be a normal part of ageing. Many people believe that if you have dementia, nothing can be done about it. While there is no cure for most causes of dementia at present, advice and support from Alzheimer associations, professional help and treatments are available. Finding out what information and services are available from their Alzheimer association can improve the quality of life for people with dementia, their families and friends.

“Family members think we are the cause for his illness – they think we deserve all that is happening to us. Other than family, we don’t really care. My mother is not very comfortable asking for help. People will blame her for my father’s problems. It is better not to ask anybody.” **Carer, India**

Awareness-raising events organised by Alzheimer associations can educate the public about dementia. They also encourage people to seek help from medical professionals as well as support from their Alzheimer association.



“I have done what I can through becoming very public about being diagnosed with dementia, what it feels like, and what you can do to help. What drives me is the thought that one day people diagnosed with dementia will not have to feel as lonely as I once did. They will receive support and help from their Alzheimer’s association and the community.”

Christine Bryden, person with dementia and ADI board member, Australia



“If people understood more about dementia, life would be less burdensome. Perhaps they would be more supportive and not critical. With all that I have gone through in caring for my mother I thought of making people aware of how to care for the elderly. Together with other caregivers, I came up with a TV talk show to address the needs and concerns of the elderly.”

Adele Joaquin, carer, Philippines



“As children and their parents sometimes conflict, care for their parents is sometimes difficult. I recognised that the good relationship between grandchildren and grandparents is very important for the care of people with dementia. This is why I made the ‘What’s the matter with my grandma?’ web pages for Alzheimer’s Association Japan. This is popular, informative and educational for adults as well as children.” **Masumi Nezu, web designer, Japan**

Promoting awareness

Raising awareness in the community is essential. It is not only the family members of people with dementia that are affected but also politicians who vote on health policies, policemen who find confused people in the street and children who do not know why grandpa can not remember their names. Raising awareness through education campaigns and events can help to change the negative public attitudes about dementia.

“When my Mum was diagnosed, I had very little knowledge of Alzheimer’s disease, or any other dementia for that matter

and spent many months trying to locate information. I try to inform and educate carers who come to our support group meeting and anyone who expresses an interest in this disease.” **Frances Stanbury, former carer and organiser of Bulawayo Alzheimer’s Group Support, Zimbabwe**

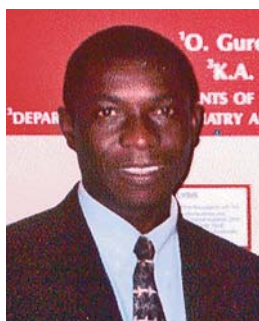
Challenging stigma

Dementia is surrounded by myth and stigma. Hiding problems can lead to tension and stress. Sharing your experiences of dementia openly with friends, colleagues or at public events encourages acceptance and understanding.

“If only people would realise that we are people who still have abilities and can play a valuable part in life, we would not have to fight so much discrimination. We need people to recognise and use our abilities.”

Shirl Garnett, person with dementia, Australia

“When I was told my Dad had dementia I was 15. I wrote an article about how our lives had been affected by Alzheimer’s, which was printed in the national newsletter for the Alzheimer’s Society. I was touched to know that other young people and carers would gain comfort and hope by reading my article. Our family feel that it is very important to have information, awareness and support for dementia.” **Lauren West, carer, UK**



“Openness and acceptance of dementia will facilitate emphasis being placed on the care of people with dementia and discourage stigmatisation or concealment of dementia cases within families. In the Indianapolis-Ibadan Dementia Study programme, monthly meetings with care-providers provided education and problem sharing. Periodic visits by nurses and physicians for the management of dementia have made care provision culturally relevant, effective and cost-beneficial.” **Adesola Ogunniyi, researcher, Nigeria**



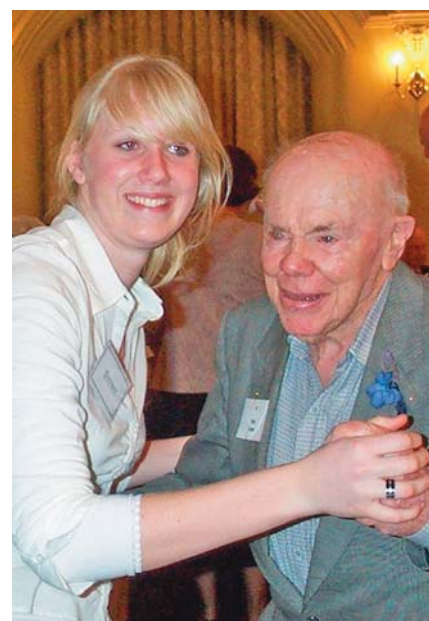
“We want to share our experiences because there is not enough awareness of the disease. We want to let others know that having a diagnosis doesn't mean life stops. Despite the circumstances, stay positive and continue to live life to the full.”

Jean Skipper and her husband David, who has dementia, Australia



“I heartily ask people to support me so that I am able to live brightly without giving up my hope until a good medicine will be developed.” **Terumichi Matsumoto, person with dementia, Japan**

“If the public and the medical profession had a better awareness, life would move on so much better. Just taking the time to convince someone of my diagnosis becomes stressful. Writing a book, developing an early stage support group and giving lectures have been a blessing for me.” **Jeanne Lee, person with dementia, USA**



One of a group of students experiencing positive interaction with people with dementia at an annual Alzheimer’s Western Australia tea dance

Engaging policy makers

Policy makers need to allocate funds for services, research and training for professional carers and doctors. This is essential to maximise quality of life for people with dementia and their families now. It is also vital to plan for future healthcare needs as the number of people with dementia is set to double over the next 15 years.

“Because of my mother in law’s illness my husband does not go for work as he needs to be at home to help us in looking after her. We need financial help. We had sent a request to the government for some help but there is no reply.” **Carer, India**

“We have shown that community health workers can be trained to identify people with dementia in the families that they visit. We are now looking at whether those same health workers can educate families and train them in practical care giving techniques. Disability benefits for older people, and compensatory benefits for their caregivers would be a great help, and we need to campaign forcefully for their introduction.”

Martin Prince, researcher, UK



“We have published new guidance this year on the best organisation of care and support. We are investing in public campaigns designed to address and remove any stigma that attaches to mental illness. In our view better awareness will produce better and more enlightened understandings, which will lead to better care and support.”

Rhona Brankin, MSP, Deputy Minister for Health and Community Care, Scotland

“Alzheimer’s disease was robbing me of my talented and loving husband; the prospect was so bleak, so swathed in stigma and ignorance, I thought that if I told it as it is, without sanitising the truth, public understanding would grow and maybe stimulate better funding for research and for carer support. Its effect has been beyond my wildest dreams.”

Barbara Pointon, carer, UK

MAKE A DIFFERENCE TODAY!

- **Speak out about your experiences with dementia – at your school, place of worship, workplace or in the media**
- **Volunteer for the Alzheimer association where you live – help raise funds and organise events**
- **Write a letter to your government – demand improved care services, training for doctors and access to treatment**

“Speak out openly, share experiences and use your creativity! Put your brain and hands into action, whatever you can do, do it and do it now!”

Lilia Mendoza, government consultant, Mexico

“Frequently people ask me why do I commit myself to the work of dementia. To work with people with dementia and their families can be frustrating but what keeps me going is the courage, resilience, patience, tolerance and above all the unconditional love that exists in these families. It is the people with dementia and their families who have made me a better doctor, a more sensitive and understanding human being and made me value my own family in a deeper way.”

Ed Chiu, psychiatrist, Australia

“On World Alzheimer’s Day this year let us celebrate our successes and work for greater awareness worldwide.”

Virginia Bell, care professional, USA

