



**Alzheimer's Disease  
International**

*The global voice on dementia*

# World Alzheimer Report 2012

## Overcoming the stigma of dementia

### SUMMARY SHEET

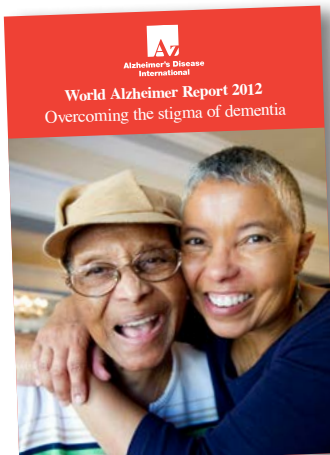
#### Background

There is now greater public awareness of dementia but not of its causes or progression. Most people are unaware of the fact that dementia is caused by a medical disorder and that the symptoms of dementia are the result of physical damage to the brain. This leads to inaccurate assumptions about its effects on the person and his or her family and negative stereotypes about how a person with dementia will behave. While public awareness of the existence of dementia has increased, that has not, as yet, led to a greater acceptance of individuals who are coping with dementia.

The report provides information on stigma and dementia, highlights best practices in the field of dementia, and makes recommendations which could help reduce stigma. A worldwide survey was conducted with people with dementia and carers on their personal experiences of stigma. Over 2,500 people from 54 countries responded, including 157 people with dementia. They shared their personal experiences of stigma and opinions about how much knowledge people in general, politicians and the media have about dementia in their country.

#### Stigma and social exclusion are barriers

The report reveals stigma and social exclusion are major barriers for people with dementia and their carers. Nearly one in four people with dementia (24%) hide or conceal their diagnosis citing stigma as the main reason. Furthermore, 40% of people with dementia report not being included in everyday life. The report reveals that people with dementia and carers feel marginalised by society, sometimes by their own friends and family members. What they want is to be treated like normal people with a focus on their abilities and not on their impairments.



Selected quotes from the survey:

*'Upon diagnosis [people think] that you have lost your intelligence and you no longer have any of the knowledge you have attained over the years. [People] no longer ask your advice on anything. [They] talk to the person you are with and not you.'*

*'People can over protect you which robs you of your independence much quicker. It should be a gradual process that is ongoing and care should be adjusted to the changes. People avoid conversation once you start showing you are having a word or thought retrieval problem.'*

*'I am afraid to tell others that I have dementia. Therefore, other people are always impatient toward me, and sometimes make fun of me.'*

*'Friends, family are uncomfortable and say they don't know how to behave 'normally' around me anymore – they didn't really give our relationship a chance to move forward.'*

*'Some of my friends have moved on as I can no longer be a part of what I used to do.'*

*'Recognition that someone with dementia is still a human being and should be treated with dignity and respect and included in everyday activities wherever possible when desired.'*

*'I am still a person with feelings and that [although] I have this diagnosis I am still a human being that just needs a little more attention but not to be condemned to a nursing home.'*

#### What did we learn from people with dementia

- 1 Other people (family, friends, neighbours, etc.) must initiate maintaining the relationship.
- 2 Include people with dementia in conversations; ask the person what is helpful for him/her to be successful.
- 3 Some people with dementia would like to be asked about their condition.
- 4 Accommodate to the new level of abilities of the person.

The full report can be downloaded from the ADI website [www.alz.co.uk](http://www.alz.co.uk)

## What did we learn from carers

- 1 Social exclusion happens to carers too.
- 2 Carers also feel marginalised.
- 3 There is a tremendous lack of understanding of what it is like caring for someone with dementia.
- 4 A lot is expected of carers from family, community and society as a whole with little support available.

## Recommendations

Stigma could be a major barrier to finding solutions for the problems related to Alzheimer's disease and other dementias, including low rates of diagnosis and service utilisation. Therefore, it is essential to take action and dispel lingering myths about dementia to reduce stigma. The following recommendations were provided by people with dementia and carers in the survey:

- Talk to people with dementia and their family carers; actively engage with them and treat them as equals. Just like a person with cancer or heart disease, ask how they are doing; ask about their memory loss, their preferences for communication, and how you can help them maintain their current lifestyle.
- Each person with dementia is unique and he or she will have tips for you on what is helpful. Some will find it helpful for you to be mindful that crowded places that are loud or distracting and may be difficult for the person with dementia to have conversations. Some will ask for help remembering words they forget, while some prefer you not correct them, but instead understand the meaning of their message.
- Do not avoid the person with dementia and only talk to their carer. Involve the person in the conversation even if they are less able to participate actively. They are still human; ignoring a person can be offensive to them.
- Be proactive in involving a person with dementia in activities. Some will need rides to social functions to stay active. Without someone initiating, the person with dementia and his or her carer may become isolated. Visit, invite the person out, and create opportunities for social engagement with other people.
- Recognise that there are different phases of the illness. People with mild dementia are still capable of doing many things with and without assistance, sometimes for many years. People with moderate dementia need guidance and support and people

with severe dementia will need total care and love. People in all phases should be included and have the opportunity to live the best quality life possible.

Societies do not have enough understanding about dementia. This includes friends, relatives and healthcare professionals. It is important to educate others about stigma so we can help people with dementia overcome it. As one survey respondent said, *'Treat us as normal people. We're still here, just a little slower and sometimes confused.'*

The report also includes examples of programmes to reduce stigma including:

- People with dementia speaking out
- Dementia friendly communities
- Outreach programmes
- Promoting earlier diagnosis
- Art and physical activity

## What would a world without stigma look like?

If there were no stigma, we might recognise people with dementia as being different, but still make every effort to include them as members of society. Physicians would diagnose everyone who has the condition and tell them the diagnosis, prescribe appropriate treatments that include drug and non-drug treatments and direct the person with dementia and their carers to support groups and other dementia-related services.

Whoever is responsible in the country – the government, health insurers or health care providers – would set up appropriate services for people with mild, moderate and severe dementia and include them in end of life care programmes. This would save costs to health systems, as less people with dementia would spend their time unnecessarily in hospitals or nursing homes and more time in the community – for everyone's benefit.

The full report can be downloaded from the ADI website: [www.alz.co.uk/research/world-report-2012](http://www.alz.co.uk/research/world-report-2012). Several supplementary materials are also available including a six minute video on stigma, an executive summary in Chinese, and two downloadable documents about how to include people with dementia in activities of Alzheimer associations and in speaking roles.

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations throughout the world. Our vision is an improved quality of life for people with dementia and their families.

Alzheimer's Disease International  
[www.alz.co.uk](http://www.alz.co.uk)  
f alzheimersdiseaseinternational  
t @AlzDisInt



The World Alzheimer Report 2012 was co-authored by Nicole Batsch, Mary Mittelman and Alzheimer's Disease International. Additional essays were contributed by people with dementia, carers and professionals in dementia care and research. The authors wish to thank the over 2,500 people that included people with dementia and carers for participating in the anonymous survey.

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