

What is dementia?

Dementia is a syndrome that can be caused by a number of progressive illnesses that affect memory, thinking, behaviour and the ability to perform everyday activities.

Alzheimer's disease is the most common type of dementia. Other types include vascular dementia, dementia with Lewy bodies and frontotemporal dementia.

Dementia mainly affects older people, although there is a growing awareness of cases that start before the age of 65. After age 65, the likelihood of developing dementia roughly doubles every five years.

A more detailed overview of dementia can be found in the *World Alzheimer Report 2009*, available from www.alz.co.uk/worldreport

The stigma of dementia

Dementia is not the first illness and likely will not be the last where the conversation and debate around stigma will be necessary. Everyone talks about the stigma of dementia, but it can be described broadly and on multiple levels. Particularly on a global level, what it means to have dementia can change from the government policy level to regional and organisational levels to the family and individual level. Understanding the causes and potential solutions at each level is important. Government and non-government organisations in some countries have been working tirelessly to pass laws aimed at eliminating discriminatory practices such as making people with dementia eligible for disability schemes. Regional organisations within countries have worked with local governments to improve access to services and delay entry to residential care, most of the time by trying to reduce stigma among family carers and health and social service professionals through increased education and regulations. At the heart of this report are the individuals with dementia and their family carers. Each faces and experiences stigma differently.

Identifying stigma is important because 36 million people have dementia worldwide and despite the best efforts in early diagnosis, treatments, care and support being offered by countries around the world – we all struggle with the same basic issue: stigma prevents people from acknowledging symptoms and obtaining the help they need to continue to live a good quality of life.

Ten key recommendations to overcome the stigma of dementia

- 1** Educate the public
- 2** Reduce isolation of people with dementia
- 3** Give people with dementia a voice
- 4** Recognise the rights of people with dementia and their carers
- 5** Involve people with dementia in their local communities
- 6** Support and educate informal and paid carers
- 7** Improve the quality of care at home and in care homes
- 8** Improve dementia training of primary healthcare physicians
- 9** Call on governments to create national Alzheimer's disease plans
- 10** Increase research into how to address stigma

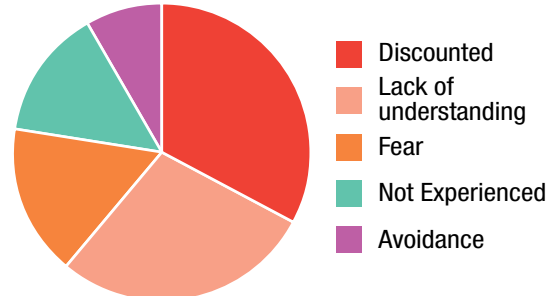
‘Stigma is an attribute, behaviour, or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one.’¹

Through this report, we hope to:

- Provide background on stigma and dementia
- Share results from a worldwide survey conducted with people with dementia and carers on their personal experiences of stigma
- Highlight best practices in the field of dementia and make recommendations which could help reduce stigma

The full version of this report also includes a selection of essays from those with expertise or experience relevant to dementia and stigma.

In your opinion, do you think there are negative associations (i.e. stigma) about people who have dementia in the country where you live?



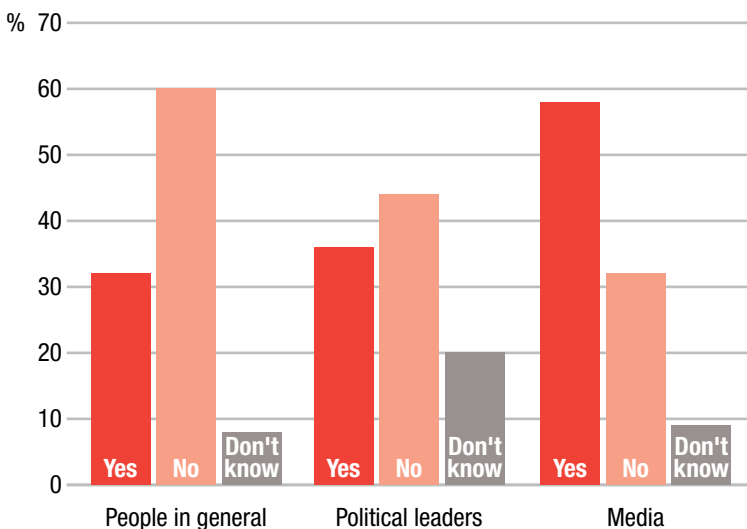
Survey results

ADI conducted an anonymous online survey of people with dementia and family or informal carers about their experiences of stigma. In this report, we provide a description of the results through a global lens, focusing on the common themes. The primary goal of the survey was to record individual experiences of stigma by people with dementia and family carers from a global sample.

The survey was accessible to all visitors to the ADI website and the survey link was emailed to contacts within the Alzheimer’s field, social care organisations, support groups, and faith-based organisations around the world. In turn, these contacts further distributed the link to their constituents and social networks within their

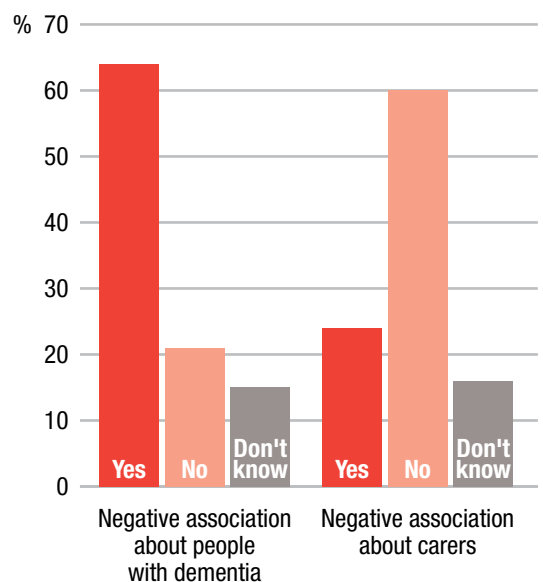
English survey of carers

Do people/political leaders/media understand dementia in your country?



English survey of carers

Do you think there are negative associations (ie: stigma) about people who have dementia or carers in the country where you live?



countries. Through support from ADI members, the survey was also translated into Spanish, Chinese and Greek.

The response to our survey was much larger than expected, with around 2,500 responses from 54 countries. Respondents not only answered the quantitative questions, but also added hundreds of narratives to elaborate on and explain their responses. In the English version of the survey, 127 respondents were people with dementia and 1716 were family or informal carers.

The people with dementia who responded were younger than average. This, and the above average education level of the respondents, may be a reflection of the fact that this survey was conducted online. More than half of the respondents have some connection to an Alzheimer organisation or service provider. The people with dementia were very likely to have received a diagnosis and were aware of available services. Thus, the people with dementia and carers who answered our survey may be less affected by stigma than those who the survey did not reach.

Understanding and impact of dementia

Nearly two out of three respondents, both people with the disease and family carers, feel that there is little or no understanding of dementia in their countries.

From the survey, it is clear that some families find it harder to cope with dementia than others. Many people are not only affected by the disease itself, but also by the reaction of family and friends. There is clearly a need for practical, emotional and financial support.

"It's very interesting to see how people close to me act. It's almost as if they are afraid of bringing up the subject. Being a cancer survivor, I know that I was constantly asked how I was doing while I was going through treatment. With Alzheimer's, no one asks."

PERSON WITH DEMENTIA, USA

By overwhelming margins, both people with dementia and carers believe that within their country there are negative associations for those diagnosed. Seventy-five percent of people with dementia responded that there was negative association, and 64% of carers agreed that there were negative associations for people with dementia.

Carers, too, confront social stigma. One in four (24%) carers reported that carers face negative associations.

People with dementia can be treated well, but it does not happen to the majority of respondents. Forty percent of people with dementia who responded to our survey do not feel that they are being treated differently than people without dementia. Another 40% reported being treated negatively, including loss of friends and isolation. One in four (24%) cited stigma as a reason to conceal their diagnosis from others.

"They take far too gloomy and negative a view of it – people didn't want to talk about cancer in the past, today it's dementia. They're surprised to meet people like me – and there are quite a few of us – who don't conform to the stereotype."

PERSON WITH DEMENTIA, UK

The issue of financial support is a problem for many families, as reported in many of the narratives. This important issue deserves further investigation to uncover the sources of the problem and what can be done about it.

"On disclosure of her diagnosis my wife was asked to terminate her employment and she finished work on that day."

CARER, AUSTRALIA

People with dementia make friends with others in the same situation: 66% of survey respondents who have dementia said that they have made friends who are connected to dementia. However, many comments in the narratives by carers and people with dementia report current and former friends have pulled away.



Michael Ellenbogen, who is living with Alzheimer's and trying to make a difference

"I have been so surprised by the stigma associated with this disease. It comes at you from all angles. People think they know what Alzheimer's is, but they don't. I see this not only from people living with dementia but many media health correspondents, physicians and organizations that are geared to helping those deal with the disease. I have learned that I do not want to share my diagnosis with people I meet until they get to know me. If I was to tell them upfront, I would be treated so differently, which I have learned. I kind of see this disease like HIV used to be. The

people who have it are so afraid to let others know, including family. I do not get it. We did nothing wrong to get this disease, and we need to speak up to let our voice be heard. We did nothing and no one should be ashamed of having it. I feel so much better when I share it with others than when I try to hide it.

"I am now a volunteer for the national Alzheimer's Association Early-Stage Advisory Group. If there is something I want you to walk away with it's that you can make a difference, but it will take persistence. Write a letter to your public official or reach out to local support organizations to create needed programs and services. Your voice and your story are powerful tools. Please get involved."

The rest of Michael's contribution can be found in the full version of the World Alzheimer Report 2012.

Background

In preparing this report, we found that the literature on stigma in dementia was very limited, and we hope that the publication of this World Alzheimer Report 2012 will stimulate discussion, research, and action to reduce the stigma of dementia.

Defining stigma

The wide variety of ways stigma is defined generates confusion and affects the target populations for stigma reduction plans. The Oxford English Dictionary defines stigma as a 'mark of disgrace associated with a particular circumstance, quality, or person'². Renowned sociologist Erving Goffman defined stigma as an attribute, behaviour, or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one¹.

What do people with dementia say about stigma?

Particularly in a report on the stigma of dementia, we value the voice of the person diagnosed. Listening to the voices of people living with dementia could help clarify what happens to a person with this condition. It is unfamiliarity and lack of knowledge that causes fear. Fear exists on both sides; in the general perception of society, but also in people with dementia who are fearful of the reactions of others. Many people with dementia have a sense of shame and inadequacy and low self-esteem. They perceive their status within society has been reduced as a result of the diagnosis³.

There is a growing body of work that suggests that stigma promotes social exclusion and reluctance to seek help^{4,5}. The stigma associated with dementia leads to stereotyping of all people with dementia as somehow falling into one undifferentiated category. More understanding is needed of the symptoms of dementia at different stages of the illness, that the symptoms change over time, and that, especially in the early stages, the person can do many of the things he or she used to do. In the middle and later stages, activities can be adapted for the person to participate and experience enjoyment.

In the early stage of dementia, this stereotyping inevitably leads to devaluing the potential contribution of the person with dementia in conversation, which results in less interaction and an eroding of the relationship of the person with dementia and family members and friends. In all stages, the stigma associated with dementia also leads to a focus on the ways in which the person is impaired, rather than on his or her remaining strengths and ability to enjoy many activities and interactions with other people. This deprives the person with dementia of the companionship of family and friends; the resulting isolation and lack of stimulation causes disability beyond that caused by the illness itself.

We believe that more understanding and awareness of the personal perspective would reduce negative connotations, lead to societal empathy, reduce fear and therefore reduce stigma.

The positive attitude of some people who have received an early diagnosis is inspiring and growing. At ADI's 2012 annual conference in London with over 1500 delegates from 60 countries, an educational track was specifically designed, planned and delivered by people with dementia. People with dementia serve on advisory committees to local, national and international Alzheimer's organisations.

What about the carers?

The concept of stigma by association reflects the fact that stigma affects not only people with the stigmatising mark, in this case dementia, but also often extends to those around them, including family members. As an individual's cognitive capacities change, support is needed and most often provided by a family carer.

The World Alzheimer Reports

The *World Alzheimer Report 2012* is one of a series that ADI has published. Each report covers a different topic.

The *World Alzheimer Report 2009* contains a comprehensive global study of the prevalence of dementia and looks at levels of mortality, disability, strain on carers and dependency. The report also includes an overview of what dementia is and examples of good national dementia plans and health service responses.

The *World Alzheimer Report 2010* provides the most comprehensive picture yet of the global economic impact of Alzheimer's disease and dementia and includes an estimate of the worldwide cost of dementia, including direct medical costs, direct non-medical costs and costs of informal (family) care.

The *World Alzheimer Report 2011* looks at the benefits of early diagnosis and intervention, based on the first-ever systematic review of the evidence on early diagnosis and early intervention for dementia.

The reports are available free from www.alz.co.uk/worldreport



Families face many problems including being afraid to bring memory loss issues to the attention of the person who has them. Moreover, some of the symptoms of the middle stage of dementia, such as agitation and incontinence, inappropriate clothes or dishevelment can be embarrassing to family members, who isolate themselves and the relative with dementia to avoid having to expose themselves to the reactions they anticipate from those outside the family. The person with dementia's symptoms (for example, poor self-care and incontinence) are often regarded as evidence of neglect⁶. Also, to the extent that individuals attempt to avoid social interactions with people with dementia, their family carers may be inadvertently excluded as well.

Stigma and old age

The stigma of dementia is made more severe because dementia is generally a disease of old age. Older age is also stigmatised, and considered to be a time of increased vulnerability and dependence. 'Despite the efforts launched against other forms of stigmatization, ageism continues to represent the most socially condoned and institutionalized form of prejudice in the world today'⁷. Stigma directly impacts older adults in the areas of driving, maintaining employment, and the ability to consent to medical procedures⁸.

Since the general expectation is that people will suffer cognitive decline with age, neither they nor their relatives are motivated to seek medical evaluation to determine the cause of the decline. Physicians are reluctant to discuss cognitive symptoms with their patients because of the stigma associated with it and the sense that 'nothing can be done'. Stigma has been identified as a major barrier to seeking a diagnostic evaluation⁹. Moreover, stigmatic beliefs of primary care physicians and therapeutic nihilism lead them to avoid evaluating cognitive function until the illness is so apparent that it cannot be ignored¹⁰.

An important consequence of the stigma associated with old age in general, and dementia in particular, is an assumption of incapacity to make decisions. We believe that this assumption can lead to a premature loss of autonomy, and dignity, which in turn fuels the loss of self-esteem associated with stigma and dementia.

Reducing stigma

Our aim in this report is to promote an enabling society for people with dementia in order to reduce stigma. We need to inform everyone that throughout the illness, people with dementia can engage, participate and maintain dignity whether living at home, in the community or in a care home. Best practices that are helping reduce stigma at all stages of the disease and through multiple levels of society must be shared.

Reducing stigma through information

While there have been qualitative and survey studies of stigma associated with dementia, there have been very few controlled trials of interventions to reduce that stigma. One randomised controlled trial conducted in the Asian community found that brief exposure to information about the symptoms of dementia, in the form of vignettes about people with the illness, led to a significant reduction in stigma¹¹. In this study, conducted in Hong Kong, older adults and those who were less educated had more stigmatic beliefs than younger, better educated adults. Those who thought dementia was treatable had fewer stigmatic beliefs. The authors pointed out, as did Werner¹², that dementia is considered to be a family disgrace (stigma by association).

Media and stigma

The stigma of dementia is fuelled by the media depiction of people with dementia in the late stages, when they are often unable to communicate verbally or care for their own activities of daily living, such as dressing, toileting and feeding themselves. Because the media focuses largely on the late stages of dementia, many people assume that as soon as the diagnosis is made, the person no longer has the ability to make decisions or care for himself¹³.

Examples of programmes to reduce stigma

Increasing awareness of dementia is a crucial component of the work currently being carried out in many countries around the world by Alzheimer associations and other organisations. A host of successful activities and programmes have been coordinated with the aim of educating the public, informal carers, care professionals and key decision makers about dementia.

Reducing stigma



The full World Alzheimer Report 2012 highlights the efforts that have been made around the world to raise awareness and reduce stigma.

People with dementia speaking out – People with dementia are increasingly coming forward to show that an active life after diagnosis is possible. The Dementia Advocacy and Support Network (DASN) International, a network of people with dementia, focusses on empowering people with dementia to become actively involved in their own care and treatment and to improve the lives of others by speaking out. The Scottish Dementia Working Group is a national campaigning group run by and for people with dementia. Similar groups exist in the Netherlands, Belgium, England and the Czech Republic.

Dementia experiences – Simulation of the experience of living with the symptoms of dementia is an effective means of reducing stigma and raising awareness among the general public in a number of countries.

Outreach programmes – Recognising the importance of raising awareness among communities of all sizes, Alzheimer associations are conducting outreach programmes utilising buses and vans as a means of disseminating information to the public and signposting to local services.

Promoting earlier diagnosis – Stigma plays a role in preventing people with dementia and their carers from acknowledging symptoms they, or a friend or family member, may be experiencing. Alzheimer associations in high income countries have conducted nationwide campaigns to combat stigma by promoting the benefits of earlier diagnosis.

Art and physical activity – Involvement in art and physical activity provides an opportunity for people with dementia and their carers to reconnect with their communities with the additional benefit of showcasing the ability of people with dementia to still partake in such activities as the disease progresses.

Learning from other areas

We can learn from other disease areas like HIV/AIDS or cancer that campaigning, lobbying and coalition building are effective at changing attitudes and driving governments to act. Professor Peter Mittler, in an essay included in the full report, suggests that the dementia community should join forces with the disability rights movement, which has successfully campaigned for better recognition of the human rights of people with disabilities, and increased inclusion in society.

Professor Baron Peter Piot, founding Executive Director of UNAIDS (the Joint United Nations Programme on HIV/AIDS), writes:

“What we must learn from the AIDS movement is that it takes a lot of work, coalition-building, campaigning and lobbying to change attitudes. Much time and effort were spent trying to overcome bureaucracy and official denial

– and stigma attached to AIDS victims. The red ribbon effectively turned this stigma into a powerful symbol for a worldwide movement. The activists were vital in putting moral and political pressure on governments to act both locally and globally.

“By investing now, we will save later. Having a global action plan to defeat dementia is the first step to making a difference to millions of people.

“Despite the obstacles, I think we can be cautiously optimistic. My experience has taught me that it takes a lot of energy and dedication to build coalitions that actually get things done on the scale that is needed. It is therefore all the more important that we work together to communicate our vision and the value of our work to mobilise the resources required to sustain our achievements so far and meet the serious challenges ahead.”

Professor Piot’s complete essay can be found in the full version of this report.

Summary

The negative perceptions of individuals and society regarding dementia may lead to the isolation of people with dementia and their carers, and also reinforce and extend isolation caused by the effects of the disease. There is a widespread assumption that people with dementia cannot take part in ordinary activities. There is also a widely held perception that they have no capacity for pleasure and cannot enjoy life. While the symptoms associated with dementia affect the way a person with dementia interacts with others, there are many activities, sometimes with adjustments, in which they can participate. Both people with dementia and their family members will benefit from continuing to engage in as many activities as they can. Moreover, people with dementia should be involved in decisions that affect them for as long as possible, to maintain their dignity and self-esteem.

Recommendations

With the number of people with dementia increasing rapidly worldwide (one new case every four seconds, more than 36 million people with the disease today and more than 115 million predicted for the year 2050), the huge economic impact of the disease (global cost of \$604 billion in 2010 – 1% of global GDP) and no cure likely in the immediate future, societies need to put much more effort into effective care and support initiatives. Otherwise, care for people with dementia will put an unprecedented burden on health and social systems.

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 to dispel lingering myths about dementia to reduce stigma. We can learn from the recommendations that people with dementia gave in our survey, including:

- 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, and 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 the 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.
- 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.
- As one survey respondent said, 'Treat us as normal people. We're still here, just a little slower and sometimes confused'.

Societies do not have enough understanding about dementia. This includes the friends and relatives

of people with the disease, as well as healthcare professionals. It is important to leverage public education.

Dementia has a huge impact on relationships. Both people with the disease and carers lose friends and feel sad about that. But there are some positive stories as well. A significant number of people in the survey feel well-treated and supported. So it can be done! Support groups and other services run by Alzheimer associations and other community-based organisations provide an opportunity to meet new people and make new friends and should be made widely available.

Give people with dementia a voice and let them speak about their experiences in public. They have proved to be powerful spokespeople for Alzheimer associations. Do not assume that it is not possible in your country. It is important to consider the abilities of the person with dementia you are working with, and think through issues such as transport arrangements for them and what time of day may be best for them. For more tips on involving people with dementia as spokespeople, visit www.alz.co.uk/worldreport2012

The voices and needs of people in the middle to later stages of dementia are also important. People in these stages can communicate in a variety of ways and are often misunderstood and undervalued; more education and support is needed for both informal and paid carers and in care home settings.

We recommend that every country develops a national Alzheimer's/Dementia plan and, in large countries, even regional plans. Good examples are available, as well as support from the WHO, ADI and Alzheimer Europe. These national Alzheimer's/Dementia plans should include initiatives aimed at creating Dementia Friendly Communities. Important elements include:

- Attention to physical environment (clear signage)
- Access and consideration for dementia in local businesses and public services
- Development of community based services
- Creation of local groups such as support groups and memory cafés involving people with dementia
- Awareness about dementia through local point of information and educational programmes

For more information about Dementia Friendly Communities visit www.alz.co.uk/worldreport2012

There is an urgent need for better training of primary healthcare physicians, who are often involved in making a diagnosis of dementia and need appropriate training to do so effectively. Healthcare providers need to adopt specific dementia care philosophies that support independence and are centred on the person with dementia. Community and residential care staff providing front-line services also require specific training to ensure services are delivered appropriately to people with dementia.

Public policy and legal efforts to include people with disabilities in as many activities as possible should be extended to people with dementia.

More research should be conducted to determine the most effective ways to counteract all aspects of stigma. In addition, new interventions that include people with dementia together with their family members, that provide pleasure to all participants and promote community involvement should be developed and tested.

A world without stigma ... how would it look?

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 disease and tell them the diagnosis, prescribe appropriate treatments, and direct them and their carers to support groups or other dementia-related services. Whoever is responsible in each 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.

“Raise awareness and educate about dementia, from an early age, so the respect and support for this type of disease becomes part of the culture.” CARER, VENEZUELA