



# Overcoming Stigma of Dementia

**STOP THE  
STIGMA**  
~~MENTAL-HEALTH  
PROBLEM~~

# Preface

Symptoms of dementia are perceived differently in different parts of the world. This includes considering dementia as a normal part of ageing, mental illness, something metaphysical linked to supernatural or spiritual beliefs or as an irreversible disease of the brain. It is very important that there is better public awareness and understanding to reduce the stigma associated with dementia. This can happen only with well developed and executed political and public campaigns to support a societal shift towards acceptance and inclusion of people affected by dementia.

Low levels of understanding about dementia lead to various misconceptions resulting in perpetuation of stigma which is prevalent in most countries at various levels. People with dementia are often isolated, or hidden, because of stigma or the possibility of negative reactions from neighbours and relatives to behavioural and psychological symptoms. The idea that nothing can be done to help people with dementia often leads to hopelessness and frustration.

Urgent action is required to improve the understanding of dementia and so reduce stigma. It is with this aim that Alzheimer's Disease International (ADI) has produced this report on stigma to coincide with World Alzheimer's Month 2012.

Overcoming stigma will help tremendously with achieving ADI's vision of an improved quality of life for people with dementia and carers.



**Peru** Memory and health screenings for the general public are frequently conducted as part of awareness-raising campaigns in the developing world



**Hungary** The Hungarian Alzheimer Society worked with the Red Cross and Rotaract and coordinated the turning off of the lights on Budapest's Chain Bridge for one hour to mark World Alzheimer's Day in 2009



**Australia** Large-scale efforts in developed countries, like Alzheimer's Australia's 2011 Fight Dementia campaign, encourage mass public involvement to promote key messages



**China** World Alzheimer's Day on 21 September is the largest coordinated international effort to disseminate information to the public



**South Korea** Support groups for carers, such as South Korea's 'Loving our wife' group, enable the exchange of experiences and creation of new friendships



**Dominican Republic** Sharing messages through the media can increase public knowledge and awareness while demonstrating solidarity for the cause



**Hong Kong SAR China** Enjoyable public events hosted by national Alzheimer associations in partnership with other local groups can be effective at drawing communities together



**Sri Lanka** Memory Walk was developed in the USA by the Alzheimer's Association and is now a popular annual event in many countries around the world

# Foreword

Alzheimer's Disease International (ADI) has released three previous World Alzheimer Reports:

- In 2009 on the global prevalence and impact of dementia
- In 2010 on the global economic cost of the disease
- In 2011 on the benefits of early diagnosis and intervention.

We also worked with the World Health Organization (WHO) on their report *Dementia: a public health priority*, which was released in April 2012.

We estimate that there were 36 million people living with dementia worldwide in 2010, increasing to 66 million by 2030 and 115 million by 2050<sup>1</sup>. Nearly two-thirds live in low and middle income countries, where the sharpest increases in numbers are set to occur as elderly populations increase.

We estimate the global cost of dementia in 2010 at **\$604 billion**<sup>5</sup>. This is 1% of global GDP and it is likely that these costs will increase in proportion to the number of people with dementia. In lower income countries the cost of health and social care may go up more rapidly, as awareness and demand for services increases.

The WHO Dementia report estimates there were 7.7 million new cases of dementia in the year 2010, or one new case every four seconds<sup>3</sup>. That is already three times as many as HIV/AIDS (2.6 million per year<sup>4</sup>). Assuming that incidence will increase in line with prevalence, since global ageing is driving both numbers, by 2050 the incidence will have increased to 24.6 million new cases annually. The average annual increase between 2010 and 2050 will be 16.15 million. This means we will have 646 million new cases in these 40 years on top of the current 36 million, unless there is a cure or a treatment that delays the onset or progression of the disease.

**682 million people will live with dementia in the next 40 years!** That is significantly more than the population of all of North America (542 million) and nearly as much as all of Europe (738 million)<sup>5</sup>.

Our healthcare and financial systems are not prepared for this epidemic. Dementia is the main cause of dependency in older people<sup>1</sup>, and we will not have enough people to care for these large numbers of people with dementia. Globally, less than 1 in 4 people with dementia receive a formal diagnosis<sup>6</sup>. Without a diagnosis, few people receive appropriate care, treatment and support.

Looking at this data, it is apparent that there is an urgent need for action. There is no time to lose! But not enough is being done. Research funding from public sources in high income countries is at a level of 10% of current cancer research<sup>7</sup>.

Stigma is something which causes an individual to be classified by others in an undesirable, rejected stereotype. Misconceptions of dementia and the people who are affected by it are a problem around the world. Stigma prevents people from acknowledging symptoms and obtaining the help they need. It causes individuals and organisations to behave in ways that are unhelpful, emphasising the symptoms of dementia rather than supporting the abilities that people with dementia have. At ADI, we believe it is a barrier to improving dementia care and furthering research. As Professor Peter Piot says in his essay in this report, 'Overcoming stigma is the first step to beating Alzheimer's disease and dementia'.

To learn more about the stigma of dementia and open a broader discussion about it, we have carried out a survey among the experts: the people with dementia and their family carers. We asked a number of people directly affected by the disease or working in the field to write essays and we reviewed relevant literature. We brought together good examples of projects and activities around the world that we believe can reduce stigma. We hope that this World Alzheimer Report 2012 will encourage others to join us in identifying and eliminating stigma, and, in turn, improve the lives of people with dementia and their carers.

1 Alzheimer's Disease International. World Alzheimer Report 2009. London : Alzheimer's Disease International, 2009.

2 Wimo, A and Prince, M. World Alzheimer Report 2010: The Global Economic Impact of Dementia. London : Alzheimer's Disease International, 2010.

3 World Health Organization. Dementia: a public health priority. Geneva : World Health Organization, 2012. ISBN 978-92-4-156445-8.

4 UN Joint Programme on HIV/AIDS. Global Report: UNAIDS Report on the Global AIDS Epidemic: 2010. 2010. ISBN 978-92-9173-871-7.

5 Continent. Wikipedia, The Free Encyclopedia. [Online] 29 August 2012. [Cited: 30 August 2012.] <http://en.wikipedia.org/w/index.php?title=Continent&oldid=509759408>.

6 Prince, M, Bryce, R and Ferri, C. World Alzheimer Report 2011. London : Alzheimer's Disease International, 2011.

7 National Institutes of Health. Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC) FY2011. NIH Research Portfolio Online Reporting Tools (RePORT). [Online] 13 February 2012. [Cited: 20 August 2012.] [http://report.nih.gov/categorical\\_spending.aspx](http://report.nih.gov/categorical_spending.aspx).

# Background

## 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](http://www.alz.co.uk/worldreport)

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 amongst 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.

## The World Alzheimer Reports

This report 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.

**‘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.’<sup>1</sup>**

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.

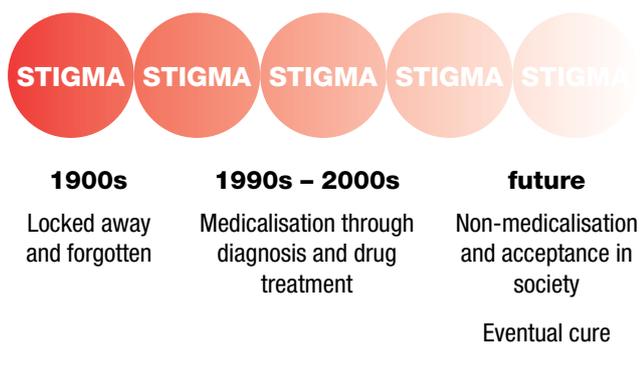
Through this report, we hope to:

- 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

We have also included a selection of essays from those with expertise or experience relevant to the topic. 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.

## Background

In the past, in most industrialised countries, the general perception of people with dementia was that they were a burden on society and should be locked away in institutions. In the 1990s, the first drug treatments became available. They were not curative, but began to provide symptom management. Additional treatments are still being developed, while a search for a cure remains the ultimate goal. In lower income countries, drug treatments remain largely unavailable and, in many places, people with dementia are still locked away from society, whether in institutions or hidden by family members.



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.

By discussing stigma, are we further stigmatising people with dementia by separating them out or providing a label? To eventually reduce stigma, society first needs to identify the causes; the false beliefs that lead to it. How does stigma affect the lives of people with dementia and carers? After a period of identification of the reasons for the problem, resources can be allocated to provide solutions. In the end, solutions create less of a need for people to be singled out as they have the necessary support and become a normalised part of society.

Several governments have developed national policies or dementia strategies to aid progress in research, provide support for people with dementia and carers, and address the health and financial impact of dementia within their countries. The national policies also include directives toward stigma reduction, pointing to stigma as one cause of the gap between prevalence estimates and numbers of people with a diagnosis<sup>2</sup>. As less than 50% of people with dementia are formally diagnosed<sup>2</sup>, stigma is certainly one probable cause. These government policies share the common goal of reducing stigma, although there are many differences in approaches being funded and tested<sup>3</sup>.

National reports in both the US and the UK indicate that Alzheimer’s and dementia are among the most feared diseases associated with getting older. The fear of getting a dementia diagnosis is greater than the fear of developing cancer, heart disease, diabetes or stroke<sup>4</sup>. Plans that exist in France, Australia, Wales and England acknowledge that ‘lack of knowledge’ is a cause of stigma and therefore their stigma reduction plans focus on increasing community awareness<sup>3</sup>.

Scotland’s national dementia plan includes ‘overcoming the fear of dementia’ as one of its plan’s five key goals. The plan seeks to improve access to diagnosis by providing general practitioners with information and resources<sup>5</sup>. The Scottish plan also includes ‘treating people with dignity and respect’, especially in care and health services. In addition, the government is actively including people with dementia and carers in the development of policies. Finland’s plan ‘will promote positive attitudes towards people with dementia in order to guarantee their basic human rights, including the right to self-determination’<sup>6</sup>.

Several countries including Australia, England and Scotland have higher education degrees in dementia as a speciality, not only within clinical training in

psychiatry, nursing or neuroscience, but also within the social sciences. Special training for future dementia care specialists through higher education elevates the credibility of the discipline.

In 'Dementia: a public health priority', a report by the World Health Organization (WHO) to which Alzheimer's Disease International (ADI) contributed, the findings led to the conclusion that:

'Dementia is a global public health challenge. A range of actions is required to improve care and services for people with dementia and their caregivers. These actions include advocacy and awareness raising, developing and implementing dementia policies and plans, health system strengthening, capacity-building, supporting caregivers and research. The actions need to be context-specific and culturally relevant.'<sup>7</sup>

For the WHO report, a survey was conducted of ADI's member organisations to identify country-level stigma practices as seen by people working in the field of dementia care. This World Alzheimer Report 2012 aims to take the survey done for the WHO report one step further by adding the voices of people with dementia and carers who are living with the impact of stigma every day. More information about our new survey and a comparison of the results will be shared in chapter 2.

## 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'<sup>8</sup>. Renowned sociologist Erving Goffman discusses stigma in terms of what he calls 'spoiled identity', meaning that a stigmatised person has become disqualified from full social acceptance. The stigmatised person's character becomes suspect and he or she is in essence viewed by others as less than human. 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 one<sup>1</sup>.

The concept of stigma has also been refined to include self-stigma, public stigma and courtesy stigma or stigma by association. Self-stigma refers to the internalisation of ideas and the reactions of those personally targeted by a stigma. Public stigma refers to the reactions of lay people towards a stigmatised individual or group. Finally, courtesy stigma or stigma by association includes the emotions and beliefs of those surrounding the stigmatised person, including family members and professionals<sup>9 10</sup>. These types of stigma feed upon and interact with each other.

Link and Phelan produced a road map that encompasses the many definitions of stigma<sup>11</sup>. They suggest stigma only exists if: 'labelling, stereotyping, separation, status

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### Box 1.1 Defining Stigma

'Mark of disgrace associated with a particular circumstance, quality, or person' *Oxford dictionary*<sup>8</sup>

'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' *Goffman*<sup>1</sup>

'Stigma can be seen as an overarching term that contains three important elements: 1) problems of knowledge (ignorance), 2) problems of attitude (prejudice), 3) problems of behaviour (discrimination).' *Thornicroft*<sup>14</sup>

'Stigma results from a process whereby certain individuals and groups are unjustifiably rendered shameful, excluded and discriminated against.'

*WPA, WHO*<sup>15</sup>

'We apply the term stigma when elements of labeling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold.' *Link and Phelan*<sup>11</sup>

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loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold.' This is an excellent description of the experience of people with dementia in their encounters with their carers, healthcare workers, the media, governments, and society.

Despite the benefits of diagnostic labels, such labels often serve as cues to signal stereotypes. The negative consequences of labelling appear to arise through two processes. First, when an individual is diagnosed with a neuropsychiatric disorder such as Alzheimer's disease, the person and those around him or her assumes that cultural ideas associated (often wrongly) with people with mental illness (for example, incompetent, dangerous) are personally relevant, which fosters a negative self-image. Second, these personally relevant cultural meanings transform into expectations that others will reject them, and these expectations can trigger defensive behaviours aimed at preventing that rejection<sup>12 13</sup>.

Measuring the impact and degree of stigma has been problematic. Thornicroft identifies how to measure stigma through measuring discrimination of people with mental illness. In *Shunned*, he describes three important elements of stigma: 1) problems of knowledge, 2) problems of attitude, and 3) problems of behaviour<sup>14</sup>. Measuring behaviours through identifying discriminatory practices and experiences of rejection and avoidance helps lead us to actions that can be taken to reduce discrimination.

In the 2002 consensus statement, 'Reducing Stigma and Discrimination Against Older People with Mental Disorders', the WHO and World Psychiatric Association (WPA) define stigma as 'resulting from a process whereby certain individuals and groups are unjustifiably

rendered shameful, excluded and discriminated against' <sup>15</sup>. By bringing public attention to the outcomes of shame, exclusion and discrimination, this definition examines those that do the stigmatising rather than the target of stigma. Let us take an example of the stigma of dementia put forward in the report: 'In both developed and developing societies, a dementia diagnosis may be used to exclude individuals from some forms of care, e.g. emergency resuscitation, in-patient units, nursing homes.' <sup>15</sup> Link and Phelan also define what they call 'the distribution of life chances', the degree to which domains such as earnings, housing, health and life itself are affected by stigma <sup>11</sup>.

By looking at the variety of definitions of stigma, and identifying how people with dementia are being discriminated against and who is doing the discriminating (or has the power to control discrimination), we can begin to make recommendations to create a better quality of life for diagnosed individuals and their carers.

### What do people with dementia say about stigma and life chances?

Particularly in a report on the stigma of dementia, we value the voice of the person diagnosed. The voices of people with dementia are an integral part of the story unfolding about stigma and these individuals should be intimately involved in helping to reduce it. An argument could be made that listening to the voices of people living with dementia would 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 diagnosis <sup>16</sup>.

There is a growing body of work that suggests that stigma promotes social exclusion and reluctance to seek help <sup>17 18</sup>. 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

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#### Box 1.2 **Autobiographies of People with Dementia**

- 1 Dancing with Dementia: My Story of Living Positively with Dementia – CHRISTINE BRYDEN
- 2 Losing My Mind: An Intimate Look at Life with Alzheimer's – THOMAS DEBAGGIO
- 3 When it gets dark: An Enlightened Reflection on Life with Alzheimer's – THOMAS DEBAGGIO
- 4 My Journey into Alzheimer's – ROBERT DAVIS
- 5 Alzheimer's Challenged and Conquered? – LOUIS BLANK
- 6 Just Love Me: My Life Turned Upside-down by Alzheimer's – JEANNE LEE
- 7 Don't Bury Me ... It Ain't Over Yet – CHARLES SCHNEIDER
- 8 Through the Wilderness of Alzheimers: Guide in Two Voices – ROBERT AND ANNE SIMPSON
- 9 Living in the Labyrinth: A Personal Journey Through the Maze of Alzheimer's – DIANA FRIEL MCGOWIN
- 10 Who Will I Be When I Die? – CHRISTINE BODEN (BRYDEN)
- 11 Alzheimer's From the Inside Out – RICHARD TAYLOR

A point to note is that all of these accounts are written by people diagnosed with younger onset, that is, diagnosed under the age of 65. We did not find any autobiographies of people diagnosed after the age of 65. Possible explanations for this could include stigma, generational attitudes, less interest in writing about or advocating for themselves or limited diagnostic sophistication early in their disease process (that is, lack of a diagnosis until the middle stages, if at all).

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to do. In the middle and later stages, activities can be adapted for the person to participate and experience enjoyment. This lack of understanding contributes to depersonalisation of the person with dementia and a lack of sympathy and understanding of the individual needs of those with the illness.

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.

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#### Reducing stigma



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. As more people are diagnosed earlier in the disease process, and are cognitively able to share their own experiences, the literature will continue to grow in this area.

People with dementia are rarely included in academic literature. However, the number of published autobiographies is growing. In an online search on Amazon.com in June 2012, for example, 272 results appeared from searching 'alzheimer's autobiographies'. Most of these included autobiographies of carers, but there were eleven books written by people with dementia (See Box 1.2: Autobiographies of People with Dementia).

First-hand accounts, the first of which was published by Robert Davis in 1989<sup>19</sup>, of the experiences of people with dementia are moving and powerful:

'I want to be the voice for all those victims who lost their ability to communicate even before anyone knew what was bringing on all these devastating changes. Many of these victims were written off by their families as crazy, 'fallen from grace,' or depressed. I want to shout, 'Be gentle with your loved ones. Listen to them. Hear their whispered pain. Touch them. Include them in activity meaningful to them. Help them stay in touch with God. Let them draw from your strength.'

Alzheimer's organisations are also active in collecting information directly from people with dementia and carers. In the *Out of the Shadows* report by the Alzheimer's Society (UK), the researchers were primarily interested in finding out if there were any perceived benefits from receiving an early diagnosis. Their finding, through interviews with people with dementia and carers, was that early diagnosis is important and valuable. Many people felt after an appropriate diagnosis they could begin to understand, adjust and cope. The participants also provided feedback on how doctors can make the diagnostic process better for individuals in the future<sup>20</sup>.

In 2008, the Alzheimer's Association (US) published findings from nationwide meetings where over 300 people with dementia were active participants. The report concluded that people with dementia want society to focus on their remaining abilities and want to maintain independence as long as possible. They wish not to be defined by decline and limitations and had suggestions during the meetings for improving relationships, helping others understand how to communicate with a person with dementia and how to keep them engaged in the daily life of their communities<sup>21</sup>.

The subject of stigma dominated the meetings. 'Many people reported a hesitation in admitting they had Alzheimer's disease for fear of negative public perceptions about the disease and its potential for causing social isolation. The potential stigma had an effect in the other direction as well, inspiring some people to want everyone to know they were living with Alzheimer's disease. So, while some felt like hiding their condition, others felt a sense of relief to be able to share what they were experiencing.'

The following are selected quotes from the report<sup>21</sup>:

- 'When people say "dementia" or "Alzheimer's", everybody thinks you're going to die.'
- 'The general public's attitude toward Alzheimer's in some instances is not very nice. In fact, excuse my expression, but I'd have to say it sucks. But it does because we let it.'
- 'There is a stigma that goes along with the disease. Many people are worried about sharing the fact openly that they have this disease because of the negative stigma. I heard someone whisper the other day, "My father has Alzheimer's." I just gave him a big hug and said, "You don't have to whisper – shout it out loud."'
- 'I'm not ashamed of having Alzheimer's. All my neighbors are aware I have a problem and there's no ridicule, no stigma, and so I wish we would get it out of our minds that we've done something; that we need to go under the table and hide.'

This positive attitude of 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. Thirty people with dementia participated at the 2012 conference from Australia, Canada, Finland, Germany, Hungary, Japan, Tunisia, the UK and USA. People with dementia serve on advisory committees to local, national and international Alzheimer's organisations including those in the UK, US, Netherlands, Australia, Germany, Alzheimer Europe and ADI. Sometimes they quote the motto from the disability movement 'nothing about us without us'.

As people continue to be diagnosed earlier in the disease process, the number of years someone will be able to live well, speak on their own behalf, make decisions about the future and actively participate in society will increase. As disease symptoms progress, the person with dementia will need more support to stay active and engaged, but it is still possible. This report will further demonstrate the opportunities for people with dementia.

## What about the carers?

As the ones primarily responsible for future care needs, family carers face a long road from helping to manage the person's independence in the early days to providing hands-on care in the later stages of the illness. Carers

are the champions of dementia care, maintaining the connection and dignity for the person with dementia. Caregiving is a physically, emotionally, financially demanding role that changes throughout the illness and much support is needed to help the carer during this time.

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. 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 neglect<sup>22</sup>. 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 by association is particularly important in Alzheimer's disease because the carer plays such a vital role in the well-being of the person with the illness. Stigma by association can lead to emotional reactions such as shame, embarrassment and guilt and responses such as decreased caregiving and concealment<sup>23 24</sup>. Furthermore, stigma can add significantly to the burden felt by family carers<sup>25</sup>. The effects of stigma by association can be particularly difficult for older spouse carers, who traditionally may have relied on their partners for personal value or a sense of identity, or were more comfortable in social situations being a part of a couple. They may withdraw and become isolated, losing the support that could lessen the challenges of caring for someone with dementia.

We believe that the stigma associated with dementia is one of the barriers to carers' utilisation of community services and obtaining support from family and friends. Moreover, many people find the acceptance of help or care to be inherently stigmatising. The reaction of the community (healthcare institutions and providers, and the general population) to people with dementia undoubtedly reinforces negative self-concepts (stigma by association) of family carers. If we can find ways to help carers to modify their own attitudes about the illness and their perceptions of the attitudes of others, we can facilitate their ability to access social support. Reducing the impact of stigma may enable carers to acknowledge their relative's illness and increase the likelihood that they will accept and receive the benefits of formal and informal support, thereby reducing depression and burden.

## 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'<sup>26</sup>. Stigma directly impacts older adults in the areas of driving, maintaining employment, and the ability to consent to medical procedures<sup>27</sup>.

The stereotypic attitudes towards older adults suggest that it is unusual if they are not cognitively impaired or physically frail. Comments like 'She is spry for her age', or 'She is sharp for her age', or 'she still has all her marbles', are made by well-meaning people in admiration of what they consider to be unusually good functioning for an older person. Thus old age itself confers a stigma based on the assumption of the inevitability of the association between age and decline.

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. In addition, the shame associated with being in the devalued group leads many people to avoid finding out whether they are, in fact, members of that group. This stigma leads many people with dementia to avoid discussing the illness with their primary care physicians until the symptoms are so severe that it is apparent to everyone. 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.' This attitude is shared by many health care professionals, who are reluctant to give their patients a stigmatising label. Stigma has been identified as a major barrier to seeking a diagnostic evaluation<sup>28</sup>. 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 ignored<sup>29</sup>.

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.

## Dementia compared to other conditions

Stigma has long been considered within contexts of other diseases and conditions. There is much to learn from how stigma has been overcome or is continuing to be confronted in cancer, HIV/AIDS and mental health. Thousands of research articles over a 30 year period have been published; first by identifying stigma, next by conducting awareness campaigns and lastly by changing

laws to reflect the individual rights of people coping with these conditions.

In 'Stigma and its Public Health Implications', Link and Phelan reason that not all medical conditions are treated equally with regards to social significance. They compare the implications of hypertension and bone fractures with those of incontinence, AIDS and schizophrenia<sup>30</sup>. Although they do not include dementia in their example, based on what we know about dementia, the pervasive public fear and the stigma experienced by individuals with dementia and carers, dementia could certainly fall into the latter category. The degree to which individual lives are impacted by the stigma of dementia has yet to be fully evaluated. Even in this report, the questions of degree are not covered. In most studies only 'one circumstance' (such as AIDS) is compared to only 'one outcome' (such as isolation)<sup>30</sup>. But the results of stigma on most conditions, including dementia, are far more complex. Multiple outcomes such as avoidance, isolation, reduced quality of life, low self-esteem, depression, loss of income, and loss of independence, just to name a few, are felt by those who are stigmatised.

Let us take diagnosis as an example. The 1970s were the first time cancer patients were told of their diagnosis. Before that, it was seen as in the patient's best interest not to tell them. The assumption was that a disease with no known cause or cure was essentially a death sentence and the person would live a better quality of life if they did not know they had cancer<sup>31</sup>. It has only been about 5-10 years since people with dementia began to be told about their own diagnosis. Possible causes include lack of diagnosis early enough for the person with dementia to understand its impact, therapeutic nihilism by physicians as previously mentioned and the pervasive myth that dementia is a normal part of ageing. To be fair, there may be reasons not to tell a person with dementia about their diagnosis, including a person's own denial of their symptoms, or lack of awareness about their symptoms. It is important for people to have the right to understand the cause, nature and prognosis of their own disease to help enable them to prepare for the future. Studies indicate that most people with dementia wish to be told of their diagnosis<sup>2</sup>. In addition, a generation of people who have cared for parents or grandparents with dementia are recognising their own symptoms earlier and taking the lead in finding out the cause.

## Dementia and mental illness

There has been considerably more research about stigma and mental illness than about stigma and dementia, perhaps partly due to the widely held belief that cognitive decline is a normal consequence of ageing. The word 'dementia' means 'mental illness' to many people, and the stigma of mental illness is well documented. Because the symptoms in the middle stage of dementia can resemble the symptoms of severe mental illness, the stigma of mental illness is also transferred to people with dementia. The confusion

of dementia and mental illness is compounded by the misuse of the term 'demented' to mean 'crazy'.

In some cultures, the shame of both mental illness and dementia is so overpowering that those affected are hidden from the view of all but those who care for them directly. Traditional spiritual beliefs about the cause and nature of dementia, and associated concerns about the effect of a person's dementia on the marriage prospects of younger family members, were found to be not uncommon in South Asian communities; and there was pressure in two groups studied to 'keep things in the family' and not expose to public scrutiny what was seen as private<sup>32</sup>.

## Stress-related stigma

There is a parallel between dementia and Link and Phelan's model of stress-related stigma of people with other disease conditions. 'The stress associated with stigma can be particularly difficult for those with disease-associated stigma. Not only are they at risk to develop other stress-related illnesses, but the clinical course of the stigmatised illness itself may be worsened and other outcomes affected, such as the ability to work or lead a normal social life.'<sup>30</sup> This is particularly true for people with dementia in the early stages who retain many abilities – including the ability to work (although not necessarily in their pre-illness capacity) and lead a normal social life. Adjustments may need to be made, but overall these things are possible with reduced stigma.

Link and Phelan specifically note the stress of people with mental illness that may cause delayed diagnosis due to the societal view of institutionalisation<sup>30</sup>. Similar outcomes exist for people with dementia. Institutionalisation may be an immediate concern for people with mental illness, but for people with dementia it may be the fear of future institutionalisation. Negative stereotypes of locked dementia units in hospitals and care homes are pervasive. Stories of people promising to never place their family member in 'one of those places' are common and unfortunately, not always realistic. Some people can live the remainder of their lives at home, but the needs of the person with dementia can affect the quality of life for the carer and the health of both individuals should be considered when making this decision.

## 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.

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Stigma has been targeted so far through three methods: information and education, awareness-raising through media, and policy efforts.

### 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 stigma<sup>33</sup>. 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 Werner<sup>24</sup>, 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 himself<sup>34</sup>.

### Public policy and future directions

Public policy and legal efforts have been more successful for people with physical disabilities than for those with mental illnesses and dementia. In a recent manuscript, Benbow and Jolley cite the ethical principles described in the report of the Nuffield Council on Bioethics<sup>35</sup> and argue that social justice requires normalising dementia wherever possible, so that people living with a dementia become a visible part of society and are, where they can, supported to carry on making an active contribution<sup>36</sup>.

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# The realities of Alzheimer's and overcoming stigma

*Michael Ellenbogen*

Alzheimer's disease and other forms of dementia affect more than 35 million people worldwide today. An astonishing fact is that today someone in the world develops dementia every 4 seconds. By the middle of the century more than 115 million people will be affected by the disease if we do nothing.

My name is Michael Ellenbogen, and I am living with Alzheimer's and trying to make a difference. I was previously a high-level manager in the telecommunication industry. In 2008, I was diagnosed with younger-onset Alzheimer's disease (YOAD) after struggling to get a diagnosis since my first symptoms at age 39. Losing my job and not being able to work had a huge impact on my life as I was a workaholic. I am now an Alzheimer's advocate and a spokesperson for the Alzheimer's Association (US) as a member of its national 2012 Early-Stage Advisory Group.

I am so frustrated, because no one realizes how seriously disabled I am. If I had a loss of limb or some other visual ailment, it would make people realize. I don't want them to feel sorry for me or pity me, I just want to be understood. So many people say you do not seem to have Alzheimer's, and that frustrates me. Let me tell you what it's like to live with this debilitating and progressive disease.

Imagine for one minute that your friend, relative or family member has Alzheimer's and has to deal with the following issues. When I go shopping and look at items, most of them never really register in my mind, even though I see them clearly. I have trouble making decisions, because I question whether I am making the right one. I can no longer enjoy my favorite hobbies, because it requires processing skills that I no longer have. I went from being a gadget person, to being threatened by technology that I no longer can use. This is what I deal with and so much more.

I go to a happy affair only to be tortured by the noise and surrounding conversations, because of the loudness that cannot be filtered out. If people try to speak with me in a public setting where there are many other conversations, I just don't understand what they are saying. This is because all of the people speaking come in at the same volume level. All the words run together, and it sounds like a foreign language.

I went from being extremely proactive to becoming much less active and motivated. I leave things around the house and don't put them away, because I don't know where they go or feel I may not know where to retrieve them again. One moment I am nice and another I may fly off the handle. I can no longer write or speak like I used to. My friends slowly become distant and usually speak to my wife. I do realize this.

I worry every day about the challenges ahead. Or even worse, I am losing my mind and see it happening, but I cannot do anything to change the course. People always say 'if I can do anything just let me know.' If I take them up on that offer, they back out of their commitments. I have become extremely surprised by the lack of public commitment to my pleas for support of Alzheimer's disease. While some may be sympathetic in the moment, there appears to be little follow-through. This is very upsetting, because I feel as though it affects me personally as well as the millions of others living with the disease. I was always there for others when they needed it and now I feel alone.

While many people just coast through the day, I have to use 110% of my processing skills to do most things, which increases the stress and frustration. The worst part about this disease is knowing that I am doing all these things wrong and have no way to control or stop it, and it's only getting worse as the

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*Michael Ellenbogen is living with Alzheimer's and trying to make a difference.*

days go by. I used to save lots of money by doing so many things around the house. Now I have lost the drive, determination and skills needed to do those things. Many times I hurt myself trying or make things worse.

I cannot begin to explain how it tears me up inside to see my spouse struggling to do the things that I once was capable of doing and know I cannot do a thing to help. I realize that one day I may no longer be able to drive and this devastates me. I see my wife becoming stressed, depressed and overwhelmed, but caregivers know it will only continue to get worse. Sadly, they keep telling themselves that they can do it all even when we know they will need help.

I, the patient, see it definitely. My wife is on the road to hell, and she does not even realize it yet, because she is so busy trying to block it all out. The worst part about all this is, I have not even reached the worst stage. That scares the hell out of me.

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.

Because of my frustration with the existing environment for people with dementia, I realized change was needed. I decided to use my few skills left to advocate. I have spent some of my last few years being on television, radio, newspapers, many blogs and working with many politicians. I also had an opportunity to speak at all of the public sessions to develop the first U.S. National Alzheimer's Plan. I did all this on my own. But that was not enough, because I ran into so many people who just did not want to get involved. 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 simple truth is, if you have not been touched by this devastating and debilitating disease yet, consider yourself extremely lucky. Sadly, it's just a matter of time before it touches you. It is my hope that my actions today may prevent future generations from suffering with this disease. So give yourself piece of mind and do something today. I hope that what I am doing will allow me to leave this world knowing that I did everything possible to make that next generation have a fighting chance. There are no excuses for not wanting to help. The human cost factor is too high, and we are all accountable to do something.

There are many organizations out there like ADI and the Alzheimer's Association that can help you. The Alzheimer's Association got me started in many ways with my new journey. It not only helped me, but it also had helped my wife as my caregiver. The Association has a website with many resources at [www.alz.org](http://www.alz.org). I encourage you to reach out today if you have not already. I would also encourage you to educate yourself.

Please join me and Go Purple on Friday, Sept. 21 for World Alzheimer's Month. I wear a purple Alzheimer's bracelet every day. And for those living with Alzheimer's, stop focusing on what you cannot do and join me in the battle to advocate. We still have so much to give, and we need to use our skills at our own speed. There is nothing to be ashamed of. I, and your loved ones, are counting on all of you ■



# Overcoming stigma is the first step to beating Alzheimer's disease and dementia

*Peter Piot*

Throughout history, we have defined ourselves in contrast to others who must be despised or feared, kept away, isolated or incarcerated. Lepers, 'witches', heretics, and, of course, the mentally ill, have all been stigmatised by the respectable folk who define and police social norms. Persecuted and pushed to the margins of society, these outcasts can be either ignored or dramatised as morality tales.

During a long career in infectious diseases, I have worked closely with stigmatised groups including sex workers, homosexuals, immigrants, drug users and HIV positive people. It has made me reflect long and hard on how we treat such vulnerable groups, and how stigmas must be overcome in order to treat disease and create healthier as well as more just societies.

Social scientists such as Freud, Foucault and Mary Douglas have written extensively on stigma, taboo, ritual purity and uncleanness. The word itself is of ancient origin, and signifies visible marks of shame, although it also, paradoxically, refers to the divine wounds of the crucifixion. Disease has long been associated with stigma, such as the visible signs of infection.

Of course, from a health perspective, some of this makes sense. We have evolved to react with disgust to disease, decomposition, filth and excrement, and at a social level to be wary of strange people, behaviour and ideas. But we have also evolved the capacity for rational reflection, and even as we take steps to protect ourselves, our families and communities, we must resist the temptation to create scapegoats or blame victims.

In my experience, stigmatisation leads to a socially sanctioned ignorance and unwillingness to engage with real issues. This is not only unjust, but often gets in the way of efforts to understand and tackle epidemics and other health issues.

In the early 1980s, AIDS emerged among gay men in the USA, but in my clinic in Antwerp for sexually transmitted diseases, I was seeing the same syndrome among heterosexuals of African origin. It was only when our paper was eventually published by The Lancet that the medical community accepted that it was not just a 'gay plague'. Decades later at UNAIDS (the Joint United Nations Programme on HIV/AIDS), we struggled with official denial in South Africa, Russia and China, but also in the West, where governments and drugs companies refused to believe a global treatment programme could be effective.

Sometimes, perhaps perversely, I think we actually need more stigma, in the sense of social and moral pressure to change harmful attitudes and behaviour – stigma of denial and inaction.

From Antwerp to Congo, and Kenya to Calcutta, I have repeatedly seen at first hand the tragic consequences of poverty, exploitation, prostitution and disease. These situations are so desperate that it is tempting to give in to despair. However I have been privileged to work with heroic health workers, carers and support groups, and throughout my career have tried to use medical science to alleviate suffering and help communities and improve their lives. In these circumstances, the moral imperative is not to judge, or to make excuses, but to act, to organise, to advocate and persuade those in power to do the right thing.

Today we face a rising tide of non-communicable diseases, including obesity, diabetes, heart disease and mental illness. Alzheimer's disease and other forms of dementia (and I know there are important distinctions here) are particularly

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problematic, not only because they are increasing rapidly, but because the stigma is to some extent invisible.

People diagnosed with mental health problems suffer from stigma in very practical ways – they are discriminated against in employment, housing and within the community. Fear of this stigma and of being shunned by family, friends, neighbours and in the workplace prevents sufferers from seeking help.

There are around 36 million people with some form of dementia in the world and this is expected to at least double over the next 20 years, making it one of the largest neglected global health challenges of our generation. The global economic cost of dementia is estimated at over US\$600 billion, and Alzheimer's Society research suggests that in the UK, one in three people over 65 will die with dementia. This is not something any of us can afford to ignore.

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.

This is never easy. AIDS forced us to confront the tremendous complexities of health and disease, and of global politics. Although virologists rapidly elucidated the nature and workings of HIV, and developed anti-retrovirals, it required a massive international effort to slow the spread of HIV and make treatment available to those who most need it – and this struggle is still not over.

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. The action plan proposed by ADI will call on leaders of the world's nations to commit to:

- 1 Invest in research and coordinate research efforts with other countries
- 2 Educate the public and health practitioners to ensure they recognise the signs of dementia. Provide information, support and access to treatment to ensure people can live well with dementia
- 3 Record diagnosis rates in their own countries to create an accurate picture of dementia
- 4 Conduct coordinated studies on the economic and social impact of dementia
- 5 Develop and share health strategies to help people reduce their risk of developing dementia.

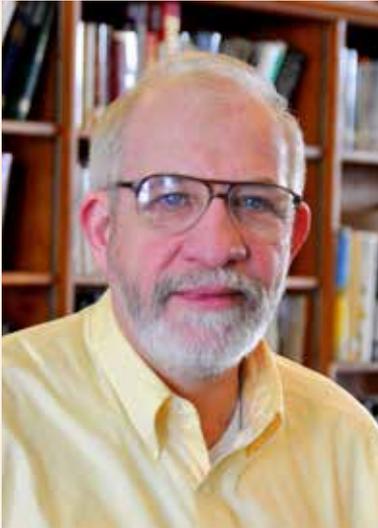
Many countries are developing good programmes, but there is a long way to go to change attitudes.

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.

A century ago, a politician from America, New York Senator Chauncey Depew, had something to say that might be relevant here:

'Follow the path of the unsafe, independent thinker. Expose your ideas to the dangers of controversy. Speak your mind and fear less the label of 'crackpot' than the stigma of conformity. And on issues that seem important to you, stand up and be counted at any cost.'

We are all mortal and we are all prone to diseases which affect our brains as well as other organs. There is nothing to be ashamed of: let us take our stigmas and beat the dogmas of despair ■



# Stigma reduction in government plans

*Michael Splaine*

Several national Alzheimer or dementia plans touch on stigma. In England, it was noted in the national plan that it took roughly three years before a patient reported dementia-like symptoms to their physician. Similar patterns of behaviour and concerns were noted in every one of the national plans that we have reviewed. Across cultures, each national plan recognised stigma as a significant barrier to accessing diagnosis and treatment for dementia and a factor that lead to social isolation. While the overall goal of stigma reduction was presented across national plans, there were variations in recommendations for methods to translate the goal into action.

To attain a baseline understanding of the general public's knowledge, both France and Australia's national plans to reduce stigma began a public survey. For Australia's Community Awareness Program, a 'dementia literacy' survey would be administered to attain a baseline understanding of the public awareness of dementia. Measure 37 of France's national dementia plan, 'studying disease knowledge and attitudes', was issued through state funding, approximately 100,000 euros, by the Ministry of Health. The objective was to 'raise the public's awareness of Alzheimer's disease, the patients' cause and that of their families, in collaboration with the patients' associations'. A qualitative study was to be conducted, through use of a survey, to evaluate non-specialists' level of knowledge and attitudes about Alzheimer's disease. Further surveys would be issued throughout the implementation of France's national plan to monitor the development of the general public's attitudes and knowledge. The data would then be released with the goal of both increasing awareness and acceptance of dementia in the general population as well as inspiring regional initiatives.

The most significant commitment was made in Australia's Key Priority Area 3, 'Information and Education', which structured a Community Awareness Program that is based upon key messages promoted by the Australian Government and States and Territories. Stigma reduction was addressed in France's national plan in Measure 42, 'making the fight against Alzheimer's disease a priority for the European Union during the French presidency.' Although no specific budget was given towards Measure 42, it provided a strong opportunity to establish Alzheimer's disease as a priority on the national agenda while carrying the unique media pull of France's term as president of the European Union.

Conveying key messages and increasing community awareness, via programs and campaigns, was the most common approach to stigma reduction across the national initiatives of France, England, Australia, Norway and Wales. Ignorance, stemming from a lack of knowledge about dementia, often translated into feelings of shame and guilt for individuals and carers of dementia patients. Informational campaigns and programs would help target those uninformed about dementia and ultimately, ideally, reduce the social withdrawal associated with diagnosis.

In their plan, the Welsh Assembly Government aimed to raise awareness through inclusion of dementia in health campaigns, communication of dementia issues through professional, paraprofessional and lay led networks and bulletins to health colleagues as well by updating voluntary organisations the government funded.

Norway's national dementia plan, with its Initiative 4.5.2, constructed a 4-year action plan for informational and educational campaigns aimed to increase openness in dialogue and social settings about the reality and challenges of

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dementia. Informational measures would be developed from the plan to make information provisions to the local government more accessible.

England's National Dementia Strategy, under Objective 1, 'improving public and professional awareness and understanding of dementia', called for development and delivery of a general public informational campaign. The key messages of England's national campaign were to promote preventative decisions about healthy lifestyle choices, stress the benefits of timely diagnosis, reduce social exclusion and discrimination, reduce anxiety while promoting understanding and to stress that dementia is a disease not a normative process of aging. Further, 'what's good for your heart is good for your head', would be utilised as a strong prevention slogan throughout the campaign.

Scotland's national initiative made distinctive recommendations to conquer negative stigma associated with dementia through research and publications. In 2008, the Scottish Government established the Dementia Clinical Research network, with over 1 million euros in funding. One objective of the research network is educating the general public to help negate the stigma associated with dementia, an example of which is establishment of a research volunteer registry that now has significant numbers of unaffected people enrolled. In addition to research initiatives, the Scottish Parliament's Cross-Party Group on Alzheimer's disease published a Charter of Rights for People with Dementia and their Carers in Scotland. The document was based on the recognition that a great stigma existed about individuals with dementia and that people with dementia and carers often experience discrimination and isolation. The document established that individuals with dementia and their care providers have the right to participate in the decision making process, are accountable for human rights and freedoms, can be free from discrimination, and should consider themselves empowered to access all levels of care and have the full range of legal human rights regardless of diagnosis. The central messages to the publication were similar to that of the other national campaigns; however Scotland's production of a 'framework' document could be a strong template for disseminating information in other national plans.

The US National Plan to Address Alzheimer's Disease includes an investment of \$8.2 million over two years, beginning this year, to support public awareness and to improve public knowledge and understanding of Alzheimer's disease (Goal 4).

More information and links to all of the plans mentioned can be found at [www.alz.co.uk/alzplans](http://www.alz.co.uk/alzplans) ■

# Survey results

ADI conducted an anonymous online survey in June 2012 of people with dementia and family or informal carers about their experiences of stigma. Over 2,500 individuals from 54 countries responded, including 2068 who responded in English and 519 who responded to versions in Spanish (282), Greek (94) and Chinese (143). In this report, we provide a description of the results through a global lens, focusing on the common themes, rather than describing the data for each country separately.

The primary goal of the survey was to record individual experiences of stigma by people with dementia and family carers from a global sample.

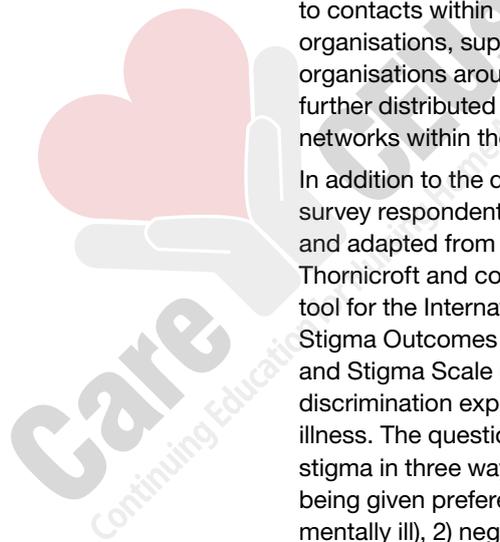
## Survey methodology

The survey was conducted over the Internet using SurveyMonkey. With this method, we were able to reach a large number of people with dementia and carers who are active on discussion boards, in chat rooms and online in general. ADI's 'I CAN! I WILL!' participants, the Alzheimer's Association's (US) online discussion boards for people with dementia, the Dementia Advocacy and Support Network International (DASNI), and the Scottish Dementia Working Group have regular active participation with each other online. Through the survey, we learned that there is a Facebook network of carers from at least five Spanish-speaking countries. Although online recruitment limits participation to people with computers, the more highly educated, and active participants of groups and programmes designed for people with dementia and carers, the information gained provides valuable insights into the issues related to stigma and its impact on people with dementia and their family members.

The survey was accessible to all visitors to the ADI website and the SurveyMonkey 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 countries.

In addition to the demographic questions about the survey respondents, the key questions were selected and adapted from two previous surveys. In one, Thornicroft and colleagues developed and validated a tool for the International Study of Discrimination and Stigma Outcomes (INDIGO) called the Discrimination and Stigma Scale (DISC) to measure the stigma and discrimination experienced by people with mental illness. The questions in this tool measure experienced stigma in three ways: 1) positive discrimination (that is, being given preferential treatment because they were mentally ill), 2) negative discrimination and 3) anticipated discrimination. In the INDIGO study, the authors used the DISC in 27 countries with 732 participants with schizophrenia in face-to-face interviews<sup>1</sup>. Four of the DISC questions were used almost verbatim and a series of questions related to unfair treatment of people with mental illness were combined into a single general question about being 'avoided or treated differently'. A follow-up question included multiple choice answers with categories of possible discriminators. In the DISC survey, each category of discrimination was a separate question. Positive, negative and anticipated discrimination were also separate. In this survey, we asked more generally whether the respondent experienced a type of stigma or discrimination and asked for additional comments or examples.

The tool was also adapted to meet the needs of respondents with cognitive difficulties and to enable the survey to be conducted through SurveyMonkey. One of the modifications to assist people with dementia in easily



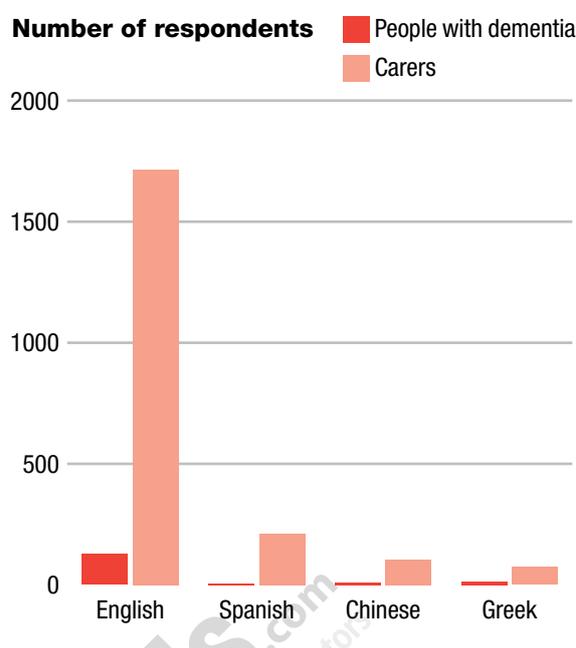
answering questions was to change the DISC 5-point answer scale to yes, no, or don't know answers. The English survey was tested with several individuals with dementia and some modifications were made before it was publicised. Room was left for respondents to provide a narrative with their answers. All questions in the survey were optional and participants were instructed that they could stop at any time.

In the second survey, conducted by the WHO in partnership with ADI, ADI member associations and other professionals were asked their opinion in an online survey. We included 10 of these questions and asked people with dementia and carers about their opinion of dementia knowledge of political leaders, the media and the general public in their respective countries. They were also asked how people with dementia could be better included in everyday life<sup>2</sup>. Similar modifications were made to these questions. By combining some of these questions with the questions from DISC, we obtained a broad picture of stigma and discrimination as viewed and experienced by people with dementia and carers themselves.

### Cultural adaptations

Through support from ADI members, the survey was also translated into Spanish, Chinese and Greek. After completion, the qualitative responses were translated back into English before including them in this report\*. Portions of the Chinese and Greek analysis were unable to be completed prior to publishing this report and will be published at a later date.

## Survey respondents



In all, 2068 people responded to the English survey. After filtering for 'persons with dementia', 'carers' and the 'other' category, 127 (6%) were respondents with dementia from 14 countries and 1716 (83%) were family or informal carers from 47 countries; 225 (11%) individuals were disqualified. In the Spanish survey, 7 (3%) were people with dementia and 211 (77%) were family or informal carers from 16 countries; 56 (20%) were disqualified. In the Chinese survey, 10 people with dementia and 106 family or informal carers responded; 21 individuals were disqualified. In the Greek survey, 13 people with dementia and 74 family or informal carers responded; 6 were disqualified†.

In total, people from 54 countries participated; however, results in this report will be aggregated, combining some countries regionally or categorising by language due to the low number of responses from most countries. It should be noted that as respondents selected themselves after hearing about the survey from a variety of sources, these are not representative samples of each country's population of people with dementia or family or informal carers. This report does not intend to say anything about cultural differences between countries. This report aims to raise issues as described by people

\* Limitations of the translated surveys included the limited amount of time available in which to conduct the translations and lack of resources available for a formal translation process. In all cases, the translations were conducted by staff or volunteers of ADI or its member associations. Unlike the English survey, the translated surveys were not tested. We received reports that care providers assisted their constituents by either verbally translating the English survey into local languages while interviewing people with dementia and carers and some respondents were assisted with the data entry onto the survey platform if they did not have access to or capabilities to use a computer.

† People were disqualified if they indicated they were not a person with dementia or a family or informal carer. The most common reason for people being disqualified was that they indicated that they were health care professionals working in the dementia field such as doctors, nurses, social workers or other (paid) carers. Others were disqualified because they indicated their family member with dementia was deceased and some did not identify themselves as a carer, for example, because they were not a close relative.

### Respondents by language and geographic locale

Percent of total people with dementia and carers

	Urban	Suburban	Rural
English	37%	46%	17%
Spanish	78%	13%	8%
Chinese	88%	6%	6%
Greek	82%	14%	3%

### Level of education

Percent of total people with dementia and carers

	Completed secondary	Completed college	Completed graduate degree
English	14%	25%	20%
Spanish	19%	31%	8%
Chinese	19%	42%	10%
Greek	30%	19%	29%

### Connection to services and programmes

Percent of total people with dementia and carers

	Participate in programmes	Do not participate / Do not know about programmes	Have made friends with other people with dementia or carers
English	54%	42% / 4%	67%
Spanish	55%	37% / 7%	64%
Chinese	50%	31% / 15%	51%
Greek	74%	23% / 3%	58%

with dementia and family or informal carers through their own words or the essence of their words as translated.

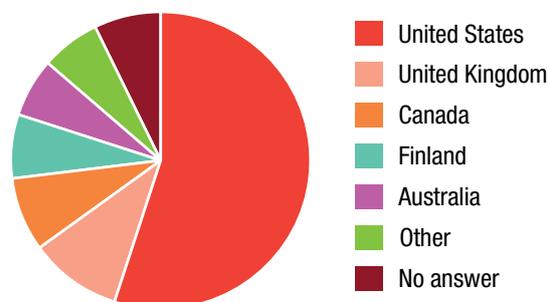
Results from the survey indicate that a majority of participants completed secondary education or above with nearly 50% of participants in the English, Chinese and Greek surveys completing college or graduate school. This indicates that survey respondents are a select group of people with dementia and informal carers with a mostly high level of education.

In addition, over half of respondents in all four surveys also participate in programmes with Alzheimer's organisations, societies, support groups or day centres and in the English, Spanish and Chinese surveys have made friends with others connected to dementia in some way. This further qualifies the group of respondents as mostly connected to services and programmes. In the future, it would be interesting to survey individuals not connected to programmes, as they are likely to be more isolated and possibly more affected by stigma.

## Respondents with dementia

English survey

### Location of people with dementia



Of the 127 (6%) of respondents with dementia in the English survey, most reported the diagnosis (or discovery of dementia) had occurred within the last five years (51%) or six or more years (33%). In the Spanish, Chinese and Greek surveys, the respondent numbers are too low to analyse. Therefore, most of the results will be summarised from the English survey with some narratives included from the other language surveys for people with dementia. Respondents with dementia have mild dementia as the nature of the survey would prevent the participation of people with dementia with more significant cognitive impairments. Some individual responses were collected from service providers who interviewed people with dementia individually and entered their comments. If an individual was unable to answer, the service provider indicated that in the survey narrative.

In the English survey 61% (71) of respondents indicated they were female and 39% (46) male. Diagnoses reported in the English survey included mild cognitive impairment (MCI) (10%), Alzheimer's disease (55%), vascular dementia (12%) and fronto-temporal dementia (FTD) (7%).

To the question **In what year were you born?** the largest group of respondents with dementia in the English survey indicated they were approximately aged between 63 and 72 years of age; born between 1940 and 1949 (38%), with a little over half of the participants (56%) being at or over the age of 65 (born 1947 or before).

Individuals with dementia responded from 13 countries. The largest percentages of respondents indicated their country of residence was Australia, Canada, Finland, United Kingdom and the United States, with the United States having the most at 55%.

## People with dementia

Highlights of the survey results are shared in this report and some comparisons are offered where the number of respondents is large enough.

### Concealing the diagnosis

To the question **Have you concealed or hidden the diagnosis of dementia from others?** 59% of the respondents with dementia in the English survey reported not concealing or hiding their diagnosis from others. In analysing the themes, people reported that they became more open over time. At least twelve individuals said that being open helps others.

“If you are asking why I don’t hide the fact that I have dementia, it is simple. I have it. If others know it, they are more apt to accept and understand.”

PERSON WITH DEMENTIA, USA

“We told our adult children right away – and told all of our friends, with whom we meet socially and for our regular music events.”

PERSON WITH DEMENTIA, USA

“I made two resolutions on my way home after receiving word. The first was: This will not be a secret!”

PERSON WITH DEMENTIA, USA

“It is easier to admit to explain evident limitations produced by disease.”

PERSON WITH DEMENTIA, USA

Of the 24% that indicated they did conceal or hide their diagnosis, they cited stigma as the main reason.

**“In most circumstances I have found that if I have disclosed that I have dementia, my thoughts, opinions, conversations are discounted and dismissed.”**

PERSON WITH DEMENTIA, USA

“I don’t want people to think I’m stupid.”

PERSON WITH DEMENTIA, NEW ZEALAND

“I didn’t [hide it] at first, thinking I could change people’s idea of what a person with Alzheimer’s disease was like. That we weren’t all helpless. But I live alone in an apartment community now and I find in this conservative area people regard me much more positively if I don’t reveal the nature of my illness. I tell those who have a real need to know.”

PERSON WITH DEMENTIA, USA

“Have told my adult children. My husband knows, my sisters know, my doctors know. Most others are unaware. I am afraid of their reaction, [for example] my landlord. I appear so normal much of the time (unless you are with me a lot) that I do not think most

people would even believe there’s anything wrong with me.”

PERSON WITH DEMENTIA, USA

In addition, special issues arise for people who are diagnosed under the age of 65. A person with young onset dementia from Scotland ‘did not want their children to be bullied at school, so delayed going public until they were older’.

Another person with dementia from the USA ‘Kept it from my co-workers. My boss and her boss are the only ones I told’.

Eight individuals indicated that they felt their diagnosis was their ‘own business’ and not for others to know about. Five people shared that they themselves still have not accepted their own diagnosis. Keeping in mind the low number of respondents in the Chinese survey, 7/10 people said ‘yes, they have concealed the diagnosis’ citing:

“Neighbours, the village leaders do not know. People who know that I am suffering from dementia will not treat us well.”

PERSON WITH DEMENTIA, CHINA

“This will affect the neighbours’ view of my family. They may mistreat us.”

PERSON WITH DEMENTIA, CHINA

### Being treated differently

There were two related questions **Have you been avoided or treated differently because of the diagnosis?** and **Have you been avoided or treated differently because of the diagnosis by any of the following?** The second question listed spouse, children, other family members, friends, neighbours, social groups, health care professionals, and by people in everyday interactions (grocery, retail, restaurants, post office) as examples. Respondents in the English survey were evenly split between yes (40%) and no (40%) answers to the first question, citing themes such as awkwardness or people changing behaviours around the person with dementia. Specific examples were provided of how family, friends and others treat the person differently. Of the 20% of individuals remaining, 10% were unsure or did not know if they had been avoided or treated differently and the rest left the question unanswered.

**“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.”**

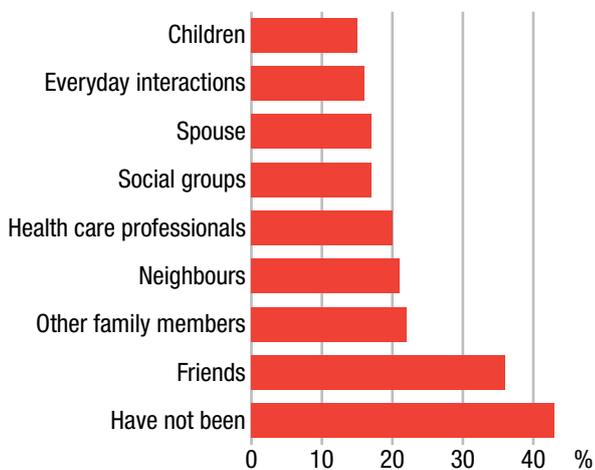
PERSON WITH DEMENTIA, USA

“People not speaking [to me]; accused by friend of lying.”

PERSON WITH DEMENTIA, UK

## English Survey

### Have you been avoided or treated differently because of the diagnosis?



"If I make a mistake, my wife tends to see it as Alzheimer related (e.g. forgetting to move the car before market day)."

PERSON WITH DEMENTIA, UK

**"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

"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."

PERSON WITH DEMENTIA, CANADA

Social exclusion was also a major theme. For example, more than 59% of the individuals who answered the second question **Have you been avoided or treated differently because of the diagnosis by any of the following?** indicated friends were the social contacts who were the most likely to avoid or lose contact with the person with dementia. Respondents felt that their children avoided them the least of all.

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

PERSON WITH DEMENTIA, UK

"'Came out' straight after diagnosis, writing or contacting over 150 friends, and received less than 5 responses."

PERSON WITH DEMENTIA, AUSTRALIA

"Some people who were friends have 'drifted away.'"

PERSON WITH DEMENTIA, USA

"My children avoid me – are not supportive."

PERSON WITH DEMENTIA, USA

To the question **Have you been avoided or treated differently because of the diagnosis?** a respondent in the Spanish survey indicated 'yes' and made the following statement:

"They call me by my nickname which is Moncho, but in diminutive, i.e. now they call me 'Monchito'."

PERSON WITH DEMENTIA (NAME CHANGED FOR ANONYMITY)

In the follow up question, this person indicated that neighbours treat him differently and added:

"I don't know if it is a different way but what I feel [sad about] is that they call me 'Monchito' [it is a diminutive so this would be like 'little Moncho' in English] instead of Moncho as they used to call me before. They are all really good people but I feel that they treat me like a child."

In the Chinese survey, a respondent shared an experience about health care professionals:

"The doctors here always say that the disease cannot be treated, treatment is only a waste of money. We have to go to big cities to see doctors."

PERSON WITH DEMENTIA, CHINA

It's important to note, however that 40% of respondents in the English survey said they have not been avoided or treated differently, citing that 'Friends and family have been extremely supportive at all times' and 'Treated differently in a very positive way. Many helpers and supporters'. There were not enough responses from people with dementia in the Spanish and Chinese surveys to report a percentage.

## Avoiding friendships and close relationships

To the question **Have you stopped yourself from having a close relationship with anyone since the diagnosis?** 70 (55%) of people with dementia said 'no'. There were very few narratives. Therefore, the following comments may not be indicative of the feelings of the other individuals who said 'no'.

"I have not had the opportunity. Many relationships haven't happened by reason of benign neglect."

PERSON WITH DEMENTIA, USA

“Met lovely people through diagnosis and became friends.”

PERSON WITH DEMENTIA, UK

“It is more difficult now, though, because I no longer am able to drive, etc.”

PERSON WITH DEMENTIA, USA

Of the 33 (26%) that said ‘yes’, most indicated maintaining relationships was too difficult. Others said that people do not understand them or they are not seeking new relationships because they do not want to be a burden.

“At some point I have to disclose that dementia is my constant companion, it ALWAYS changes the relationship which soon falls to the wayside. It does help if the person is educated with dementia, but still most are not ready to go down that road with yet another person they care for.”

PERSON WITH DEMENTIA, USA

“I have difficulty looking after my own needs so cannot maintain others’ needs e.g., friendships. Going to the gym is getting more difficult to socially interact.”

PERSON WITH DEMENTIA, UK

“Friends – I can’t talk to them without stuttering.”

PERSON WITH DEMENTIA, NEW ZEALAND

“Initiating dating relationships is now extremely difficult. Further, I stay away from some social events with good friends because I feel I would be a burden. Recently, I declined an invitation to a nephew’s wedding because I felt my being there would detract from the enjoyment of my relatives in this celebratory event.”

PERSON WITH DEMENTIA, USA

“I am single and the relationship I was in ended fairly quickly. At that time I could not see taking it to the next level so I ended it.”

PERSON WITH DEMENTIA, CANADA

**“I have been hesitant to start potential new friendships since the diagnosis because I am afraid that they might notice mistakes on my part and think it strange i.e. language mistakes when talking sometimes. And I would not want them to know of my MCI, as I feel strongly that they would then either treat me differently or would opt out of our friendship altogether. So I do not seek new friendships.”**

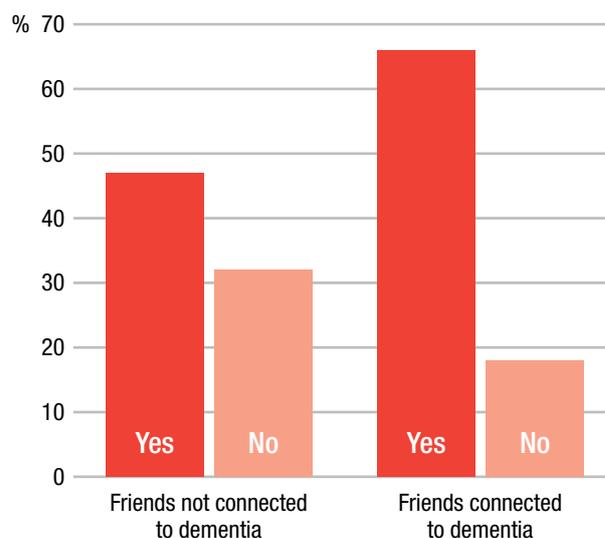
PERSON WITH DEMENTIA, USA

“I only make friends with other diagnosed dementia people.”

PERSON WITH DEMENTIA, AUSTRALIA

In the Spanish survey, a respondent who indicated stopping herself from having close relationships said,

### Friends connected with dementia



“We used to go out very often with a married couple but now we do it sporadically.”

In the Chinese survey, a person said, ‘I am afraid to tell others that I have dementia. Therefore, other people are always impatient toward me, and sometimes make fun of me’. Another person said, ‘My family wanted to harm me’.

In making friends since the diagnosis occurred, 47% of people with dementia in the English survey report they have made friends with both people not affiliated to dementia in any way, 32% said ‘no’ and 3% said ‘don’t know’. Of those that have made friends with people affiliated with dementia (that is, another person with dementia or carer), 66% said ‘yes’, 18% said ‘no’ and 2% said ‘don’t know’.

If they have an opportunity to make friends with people not connected to dementia, they find those friendships through their faith-based activities, in a senior residence or other living arrangement with other people, and with neighbours. Some cited maintaining their existing friendships.

“Neighbour – she helps me with knitting.”

PERSON WITH DEMENTIA, NEW ZEALAND

“Some very loving and understanding neighbours who take me as I am.”

PERSON WITH DEMENTIA, UK

“Only 1 person. I met a young girl who I believe was about 21 years old. We have spent hours talking over the years and have become part of each other’s family. I was there for her wedding and am now awaiting the birth of her first child. We have acknowledged to each other that we have each changed our path since meeting each other. This is a

very unique person as most people avoid any close relationships.”

PERSON WITH DEMENTIA, CANADA

For individuals making friends with people connected to dementia, they find each other through support groups, online or through organisations such as Alzheimer associations.

“Alzheimer’s support group. Walking group and cafe outings.”

PERSON WITH DEMENTIA, NEW ZEALAND

“Online only. Because I live in a rural area, there are no support groups for people with younger onset.”

PERSON WITH DEMENTIA, USA

“Most exceptional to my well-being were the people connected with the Alzheimer’s Association ‘Early stage’ memory group.”

PERSON WITH DEMENTIA, USA

In the Chinese survey, two comments were provided, both by people from China. One person said, ‘I do not know whether other people I am talking with suffer from dementia’. Another said, ‘[I] know a few patients and ask how they are treated and what medicine they are taking’.

## Awareness of dementia

The majority of respondents (55%) are from the United States; however, we can see a connection between the opinion people with dementia have about negative opinions about dementia within their country with what they say about the awareness of people in general, political leaders and the media.

## Is there awareness of dementia amongst people in general, political leaders, media in the country where you live?

The majority of comments to these questions centre on a true lack of understanding of what people with dementia need and what it takes to keep them active in society. People with dementia said they felt that political leaders do not care unless their own family is affected by dementia. People that commented also felt that media attention is growing but much of it is a negative view of a person with dementia in a care home or in the later stages. Some pointed out the language used in the media such as ‘sufferer’ and ‘victim’ and hope to see the language change.

“People have heard about it but the majority does not know what exactly this illness is. I think they are scared and do not know how to behave. It is easier to ignore things and the people with the illness. In my opinion it won’t change unless they will be educated but change will only happen if the government is willing to do something but they clearly are not.”

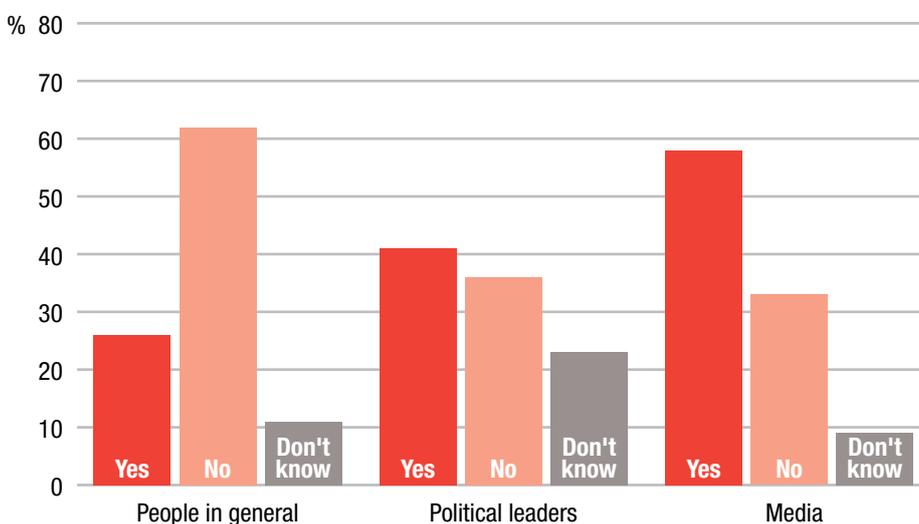
PERSON WITH DEMENTIA, HUNGARY

“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.”

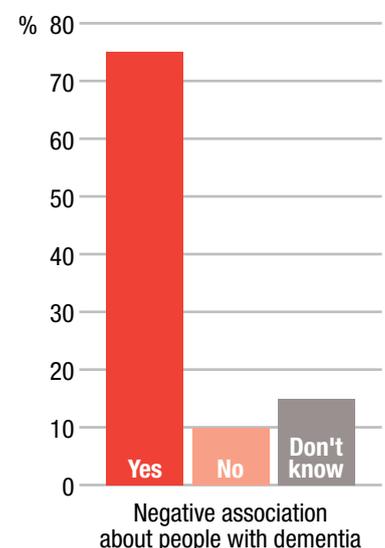
PERSON WITH DEMENTIA, UK

“People seem only to have a cursory understanding but do not understand the specifics of the various

## Is there awareness of dementia amongst people in general, political leaders, media in the country where you live?



## Do you think there are negative associations about people with dementia in the country where you live?



types of dementia and the resulting differences in symptoms.”

PERSON WITH DEMENTIA, AUSTRALIA

“I think that those who do have some understanding of what dementia is, think of it only in terms of the late form of dementia – quite advanced – and assume that all people with a dementia diagnosis are like that, severely affected. And I think that a lot of people, if not most, do not understand what dementia means at all.”

PERSON WITH DEMENTIA, USA

“Political leaders do not really care, unless someone close to them is afflicted with dementia.”

PERSON WITH DEMENTIA, USA

“The Scottish Government is getting the message although the financial situation can be difficult to make things better.”

PERSON WITH DEMENTIA, UK

“They are aware of the cost of care, but have absolutely no awareness of the need to make accommodations for the complexity of life for people with dementia so they can remain in the mainstream.”

PERSON WITH DEMENTIA, USA

“Increasingly, but that doesn’t necessarily bring services or resources or prevent serious human rights abuses in services. Leadership can be expressed by ‘driving up standards’ something which politicians do for children but not for the elderly (with or without dementia).”

PERSON WITH DEMENTIA, UK

#### For how dementia is perceived by the media:

“Although it is not always a good awareness it can be negative and they don’t show people trying to make the best and live a good quality of life with dementia but the SDWG [Scottish Dementia Working Group] are trying at every opportunity to change that.”

PERSON WITH DEMENTIA, UK

“It’s getting better. More people with dementia are being asked for their opinion and some interviewers are even willing to wait or listen to the answer.”

PERSON WITH DEMENTIA, UK

“Stereotype of late stage old person in nursing home is all that is shown when dementia is mentioned – never positive images or only a few and counteracted by the usual negative ones.”

PERSON WITH DEMENTIA, AUSTRALIA

“They only comment on things which they think will benefit their careers and don’t listen when you say we are not sufferers. Ten minutes ago I watched a TV programme Secret Millionaire, which frequently mentioned dementia sufferers. They didn’t have a clue.”

PERSON WITH DEMENTIA, UK

“The media still portrays dementia as one thing: end-stage Alzheimer’s disease. There is little awareness of other types of dementia or of stages of Alzheimer’s. There is such a climate of fear that most people are in denial about symptoms in themselves and/or loved ones and do not get tested at early stages when medication might ameliorate some symptoms.”

PERSON WITH DEMENTIA, USA

In the Spanish survey, a respondent commented about political leaders, ‘I believe they all have an awareness of what dementia is, but to actually be concerned to do something, that’s a different thing.’ And said, ‘The media is aware of what is dementia is, and there has even been a program that focused on the subject but it is in general an issue of little interest, rather the topic is indifferent to the media both TV and press and radio’.

### Stigma about people with dementia

To the question **In your opinion, do you think there are negative associations (i.e. stigma) about people who have dementia in the country where you live?** over 75% of the respondents with dementia said ‘yes’ and 42 people identified negative examples about people with dementia in their country. The most common negative association was the feeling of being discounted or marginalised by others (28%). The lack of understanding of what to do when having a conversation with a person with dementia or how to involve the person more was also a common theme (24%); 14% recognized fear in others. And, the reinforcement of the theme of avoidance by friends appeared a few times in answers to this survey question. Five people indicated they had not experienced negative associations in the narrative section.

“No question. I think there is a perception that the disease is a personal short-coming.”

PERSON WITH DEMENTIA, USA

“They think I’m stupid and can’t talk properly.”

PERSON WITH DEMENTIA, NEW ZEALAND

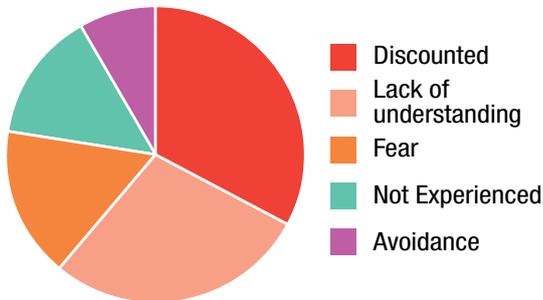
“People think that those with dementia are crazy, mentally unglued and unstable and, therefore, are to be avoided because how would you know how to communicate with them anyway? And wouldn’t it be so awkward and embarrassing to have to be with them at all? Many people are afraid of dementia (could I get it myself, even?) and want to stay as far away from people with it as possible. It terrifies them.”

PERSON WITH DEMENTIA, USA

“My cognitive abilities are still fairly high. However, when I have difficulty remembering words or am slow in my responses, I sometimes encounter impatience, people trying to find my words for me, exasperation, and so forth. My uncle had Alzheimer’s and I remember that his children became embarrassed to

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



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go out to restaurants with him because they did not know how his behavior would be.”

PERSON WITH DEMENTIA, USA

“I was asked to resign from my job the day I notified my manager of my diagnosis (the day after diagnosis). I finished work that day.”

PERSON WITH DEMENTIA, AUSTRALIA

In the Chinese survey, a respondent shared, ‘Other people will not show enthusiasm, show patience to you, or they may lie to you’.

## **Coping with stigma**

To the question **Do you have personal skills and abilities to cope with stigma?** 59% said yes, 12% said no and 28% said they did not know. In the narratives, people with dementia described that it’s a skill that develops over time, having friends helps them get through, and some people indicated turning to their faith for support. The majority of people who wrote narratives indicated that becoming educated about the disease is both helpful and helps them educate others. The other key theme from this question revolved around learning how to adapt to lost skills.

“I think my skills have developed over time, getting beyond the initial scare (‘you will probably be institutionalized within 3 years’ – 12 or more years ago) finding kindred friends, realizing that lost skills can be replaced – bolstered with others, that many of the outcomes of dementia can be embraced and enjoyed ... Reading a great book and enjoying it yet again and again with a ‘deja vu’ atmosphere of pleasure.”

PERSON WITH DEMENTIA, USA

“I try to inform people when possible about dementia and the different types that affect those with them differently so they can understand how we’re all functioning on different levels within the disease ... explaining that it is a degenerative disease and

sometimes a slow progression before they will see the symptoms, that they then can identify as ‘dementia’.”

PERSON WITH DEMENTIA, AUSTRALIA

**“I think I was very lucky in having life experiences that gave me these skills to work on and develop and change as the disease progresses. I was also the primary care partner for my father who had vascular disease. I believe this gave me great insight into my own journey and made me realize some of the things I did well and some of the things that were not done well at all.”**

PERSON WITH DEMENTIA, CANADA

“I just consider it the problem of the person who holds the opinion – rather than mine. But if encountered too often, it saps morale. I belong to other groups that are minorities locally but this is one where my competency is in question.”

PERSON WITH DEMENTIA, USA

**“I’ve armed myself with information about Alzheimer’s by reading lots of books and articles. I think information and knowledge is the best defence against stigma.”**

PERSON WITH DEMENTIA, USA

“I am able to help allay the initial fears people have about my diagnosis when I first talk to them about it because I can keep the conversation going and let them know that although I have this disease – I am doing okay and coping the best I can. When you first tell people you have dementia – they don’t know what to say ... if you (the people with dementia) are able to keep the conversation going – the situation will be much more comfortable.”

PERSON WITH DEMENTIA, CANADA

Even though there were many positive responses to this question, people with dementia are very much aware of the difficulties of their situation, recognizing there are good days and bad days and some are ashamed of having the condition.

“I have my faith; that is the only thing that sustains me at times.”

PERSON WITH DEMENTIA, USA

“I am very, very ashamed of having dementia.”

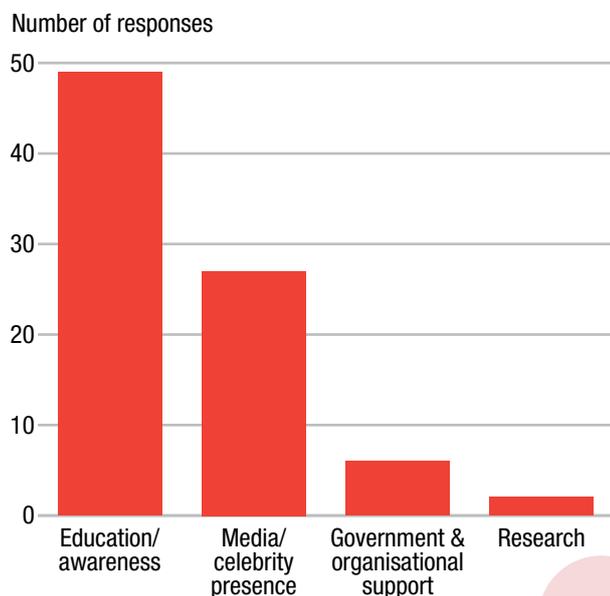
PERSON WITH DEMENTIA, ZIMBABWE

“It depends on whether I am feeling good about myself on that day.”

PERSON WITH DEMENTIA, USA

## Reducing stigma

### What do you think can be done to reduce stigma?



To the question **What do you think can be done to reduce stigma?** 49 people indicated education and awareness was a priority. Having media attention that was more positive was indicated by 27 people and 6 individuals indicated more support from governments and organisations was important.

“Increase public awareness by all media to show the abilities of sufferers particularly in the early stages and those with younger onset.”

PERSON WITH DEMENTIA, AUSTRALIA

“To reduce the fear, to have more of an understanding of dementia that I am still a person with feelings and that because 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.”

PERSON WITH DEMENTIA, AUSTRALIA

“Education, change the ‘look’ of dementia – it is not always the doddering helpless old person in a wheelchair, in a rest home being attended, being a complete burden to family.”

PERSON WITH DEMENTIA, USA

**“Showing more positive media stories of living well with dementia. Showing people with dementia using their strategies to live life to the best, coping with the physical and emotional social impacts of this disease.”**

PERSON WITH DEMENTIA, UK

“Raising of awareness in media, education and amongst health professionals.”

PERSON WITH DEMENTIA, UK

“More information to the public regarding this issue. Most people are afraid to ask a patient and thus keep in the dark about dementia.”

PERSON WITH DEMENTIA, USA

“Dollars for research on diagnosis, medication and eventually a cure. Not for me but maybe for my children and others.”

PERSON WITH DEMENTIA, USA

“Education and awareness programmes; dementia symbol – just like a wheelchair symbol, where some of the staff in shops, banks, taxis, etc. have had some training or education in dementia.”

PERSON WITH DEMENTIA, AUSTRALIA

“Persons with dementia should be treated as normal persons.”

PERSON WITH DEMENTIA, FINLAND

“We need to see more people on TV with dementia in early stages. People like Glen Campbell and Pat Summitt in US have really helped. Also, programs that pair children with dementia patients are wonderful for breaking down stigma.”

PERSON WITH DEMENTIA, USA

In the Spanish survey, someone from Venezuela said, ‘Improve social programmes and research as well as training, humanization. Improve the facilities in places where the diseases are addressed’.

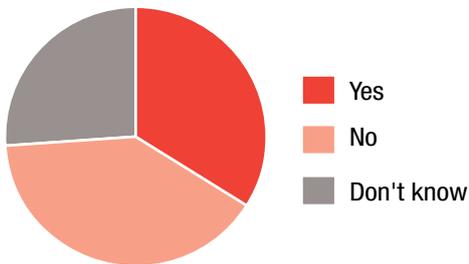
And, another person said, ‘Talk about this disease, so that people know that no one is free [from being affected] and that it can touch anyone’.

Several respondents in the Chinese survey provided comments. One person thought it was important to keep dementia concealed. Another indicated that with the help of local organisations, stigma could be reduced. And another indicated ‘the government is clearly concerned’. One person commented, ‘Dementia and cold are diseases, but the cold was soon healed, others do not hate. Once dementia is cured, others will not hate as well’.

## Inclusion in everyday life

To the question **Are people with dementia included in everyday life?** 34% indicated they feel people are included citing they themselves are doing many things like playing golf, and volunteering. 40% indicated that people with dementia are not included and mentioned issues like access to programmes, transportation needs and stigma remaining as the main barrier. Some felt that for the person with dementia to be included ‘it’s up the family’; in other words, does the family support the individual with dementia in getting out of the house. People who limit themselves from participation in

**Are people with dementia included in everyday life?**



everyday life said things like, 'I don't know as I have withdrawn myself from such social activities'. And, 'Bottom line is I am ashamed of it'.

Some mentioned that it might depend on the stage of dementia and abilities and how other people have a lack of understanding about engaging with people with dementia:

"I can only go on my own experience and would have to say yes, they are. But again I am in the early stages, and what happens when dementia is more advanced I cannot say."

PERSON WITH DEMENTIA, AUSTRALIA

"It is hard to say it can be a post coded lottery depending on where you live life is busy and not really a friendly place for people like me who need a slower pace [and] more time when society today is fast and time is something that is limited."

PERSON WITH DEMENTIA, UK

"There are facilities and various designated places for people with dementia but the general public appear to have little knowledge of it or of how to approach and talk to the dementia patient."

PERSON WITH DEMENTIA, USA

**"I think they can be, but choose not to be because they cannot handle some of the situations. People don't consider what we as patients feel and go through in certain situations."**

PERSON WITH DEMENTIA, USA

Many people identified stigma as a barrier and said:

"[I] tend to be isolated and meet only in groups of others with dementia. This is good as people can feel safe, but bad as they miss out on a lot of everyday community life."

PERSON WITH DEMENTIA, UK

"We're not there yet. For example, the city's senior adult community centers do not yet have programs

for people like me, who are already living with early Alzheimer's. They could!"

PERSON WITH DEMENTIA, USA

"Not always. I would still like to be on boards but because of my diagnosis [am] not able to be. Even though I have younger onset at the early stage [it] does not mean that I do not have ideas and suggestions that could help an organisation address some of their issues and be involved in strategic planning."

PERSON WITH DEMENTIA, USA

Some interesting positive examples came out as well:

**"It depends on their age and their living circumstances and what you consider 'everyday life'. Are people in care facilities living 'everyday life'? Are people locked in offices for 50 hours a week living everyday lives? Are those of us retired with disability living everyday lives? Yesterday I tutored an unemployed woman. Today I'm at home doing the laundry is that everyday life?"**

PERSON WITH DEMENTIA, USA

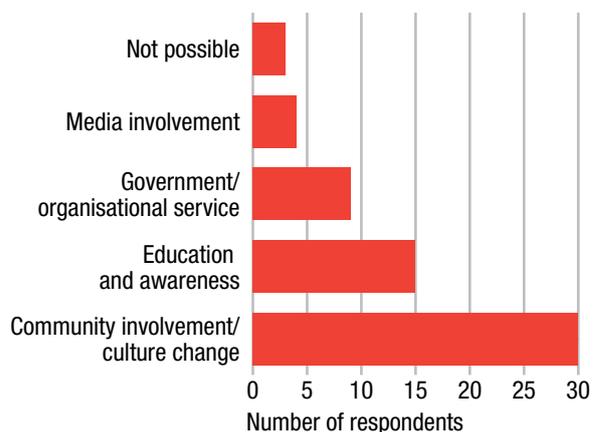
"Varies tremendously on the attitude of the person who has the disease, their care partners and the stage they are in."

PERSON WITH DEMENTIA, USA

**How to include people with dementia**

In order to improve the degree to which people with dementia are included in everyday life, we asked **How can people with dementia be included in everyday life?** Many suggestions were offered around themes of community involvement or change culture (30), education and awareness programmes (15), government, or organisational services (9). Media involvement was mentioned by 4 people and 3 people mentioned they

**How can people with dementia be included in everyday life?**



did not think it was possible due to dementia being a progressive condition.

### Community involvement and culture change

“To be treated as they are not going to catch what I have, or to minimize what I have so I want to be included.”

PERSON WITH DEMENTIA, AUSTRALIA

“Not to be ignored and written off by mental health teams as ‘no hopers’ but finding things that they can contribute to.”

PERSON WITH DEMENTIA, UK

“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.”

PERSON WITH DEMENTIA, UK

“Making it easier to live at home with family members, including social workers and other help and financial help prior to hospice.”

PERSON WITH DEMENTIA, USA

“The problem is not having them included out of politeness while they really would rather not see you. We no longer have friends.”

PERSON WITH DEMENTIA, USA

**“Treat us like normal people. We’re still here, just a little slower, and sometimes confused.”**

PERSON WITH DEMENTIA, CANADA

“Ask them, encourage them, enable them.”

PERSON WITH DEMENTIA, USA

“Hard to say; everyone is different. Some may want to be involved with activities; others may feel that they are doing enough at home. Treat the person with dementia as a person. If they are treated as a ‘patient’ they will act as a patient (that is, as if they are sick).”

PERSON WITH DEMENTIA, CANADA

### Education and awareness

“By making others aware of the disease so it’s socially acceptable.”

PERSON WITH DEMENTIA, USA

“Education, education, education, awareness campaigns, and symptoms treated as disabilities.”

PERSON WITH DEMENTIA, AUSTRALIA

“A better understanding by the public [of] what an individual with dementia goes through.”

PERSON WITH DEMENTIA, USA

“More publicity. More demonstrations of the capabilities of people with dementia and their carers.”

PERSON WITH DEMENTIA, UK

In the Spanish survey, it was important for one person to continue to have purpose within the home, ‘Do small tasks at home (hand a dish, cutlery, put away paper) which is what I do in my house, always under the control of my wife or the caregiver’.

## What did we learn from people with dementia?

The people with dementia who participated in this survey are courageous, candid and have shared meaningful contributions about how they can be better treated by society. We learned that people with dementia are aware that other people are afraid to talk to them. They would like to be included in conversations. For some people with dementia it is acceptable and encouraged to ask about their memory loss.

People in the survey have suggestions for how you can better communicate with them; as the person with dementia best knows his or her own limitations. Survey respondents mentioned that crowded places are loud and distracting. It may be difficult for the person 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.

People with dementia also shared how disheartening it is that people avoid or ignore them. Others, whether family, friends, strangers or health professionals tend to address their carer and no longer include them in the conversation. While people with dementia are aware of their own limitations, they would like their social circles to adapt and accommodate to their new level of abilities. One example from the survey was the gentleman who mentioned he still enjoys playing golf with his friends however keeping score has become less important as he is

undoubtedly aware that he can no longer do so.

People with dementia also shared the fact that they feel more isolated and withdrew from regular activities, either because they could not keep up or because they wanted to protect their friends from having extra burden. Friends will need to take more of the initiative for the person with dementia. Providing transportation, maintaining visits in the home, and providing social opportunities were mentioned by people with dementia in their examples.

We must listen to what people with dementia say, and act on it. We have based recommendations of this report on their responses (see chapter 4).

## Carers

People with dementia and carers participated in the same survey. Carers had two additional questions that included relationship to the person with dementia and level of assistance with daily tasks. For carers, only results from the English and Spanish survey narratives have been analysed to date. The Greek and Chinese surveys will be analysed for future publication.

In the English survey, 1716 of the respondents indicated that they were carers. 86% (1402) were female, 14% (227) were male. The most common relationships to the person with dementia reported were child 778 (48%) and spouse 439 (27%). In addition, 53% said the person they care for with dementia was diagnosed 1-5 years ago, and 35% said diagnosis was 6 or more years ago. 7% (119) provide no assistance, 16% (256) provide a little assistance, 31% (491) provide some assistance, 32% (514) provide a lot of assistance and 13% (215) provide total assistance to the person with dementia. In the Spanish survey, 211 respondents were carers, with 84% (162) female and 16% (31) male. The relationship to the person with dementia was child for 123 (63%) respondents and spouse for 27 (14%). In addition, 45% said the person they care for was diagnosed 1-5 years ago and 39% said 6 or more years ago. 4% (7) provide no assistance, 6% (11) provide a little assistance, 22% (41) provide some assistance, 43% (81) provide a lot of assistance, and 26% (49) provide total assistance to the person with dementia.

The majority of carers in the English survey were born between 1950 and 1959. The oldest of the carers were born in 1921 and the youngest born in 1995. In the Spanish survey, the majority of carers were born between 1960 and 1969.

Carers in the English survey responded from 47 countries. Over 63% of the respondents were from the United States and the next largest percentages were from Europe (11%), Canada (10%), Asian countries (4%), and Australia/New Zealand (3%).

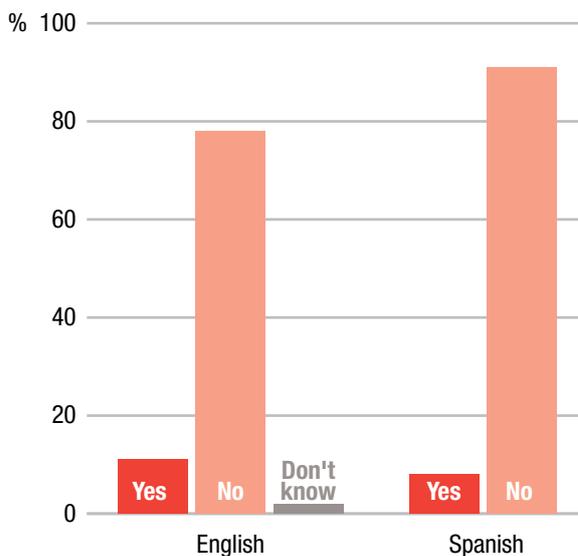
Carers from 16 different countries responded to the Spanish survey. Spain was the single country with the highest proportion of respondents at 33% followed by Uruguay with 9%, other Latin American countries and also the US.

### Concealment

In the English survey, the majority of respondents (78%) to the question **Have you concealed or hidden the diagnosis?** said 'no', 11% said 'yes'. The themes from the narratives included carers becoming open over time. Most felt that it was necessary to discuss the person with dementia's symptoms with others. Some reported not accepting the diagnosis themselves and over 50 carers indicated that by being open about the diagnosis, they receive more help and are able to help other people going through similar situations.

"Initially I (as daughter) considered the symptoms of my mother's dementia as my mother's personal and

### Have you concealed or hidden the diagnosis?



private business. Later in the process I became more open and willing to share experiences with other caretakers."

CARER, ARUBA

"At first I did. Then later, I could not and there was no point. I was worried about keeping my own job more than anything else. I still am. I do not talk about what I live with at work for fear they will think I cannot handle my position."

CARER, USA

"My husband (the diagnosed) was very open with people from the beginning and even called former co-workers to tell them what the 'problem' had turned out to be. Since he was so open, I followed his lead. I did not tell everyone in my place of business immediately as I thought I would need their good will later on. As my husband progressed and required more attention and planning, I advised those I work closely with, and all have been extremely considerate of the challenges and my need to plan for business trips and extra hours."

CARER, USA

"We tell everyone that my spouse has dementia or memory problems. We don't feel it's a stigma. It's no difference than when we told people he had a stroke, or heart failure. It's a medical condition. He's early in the disease. Forgets a lot of details, but can easily hold a conversation."

CARER, USA

**"I believe it is important to engage as much as possible with those that understand this illness, to learn and to share for increased knowledge,**

**appreciation, enhancing compassion and care-giving effectiveness.”**

CARER, CANADA

“I have been very open and honest about her diagnosis to others because I believe it helps others understand her sometimes inappropriate behaviour.”

CARER, USA

Similar to respondents with dementia, carers mentioned stigma as the reason for not disclosing right away, but other things happen later on that require them to share the diagnosis. Others felt that it was their family’s business and that sharing was not appropriate.

“I have been open with the diagnosis but the rest of my family has not openly shared. Only in times of need do they discuss it with people outside of our family.”

CARER, USA

“Mom and Dad were very good at hiding what was happening. Then Dad left on a trip and I was completely shocked at how much Mom could not do herself. This was 2 years ago now. Her doctor did not notice anything until this year because she just gets very quiet when we are away from home. She did not want to be medicated (we talked about it in the beginning when she could still make decisions) so we have not had it diagnosed.”

CARER, USA

“In the beginning, I was ashamed and didn’t tell friends and neighbours. I tried to cover up my husband’s mistakes.”

CARER, NETHERLANDS

“At first, we did not openly talk about it as my mother was sensitive to the issue. Now that she doesn’t comprehend much, we may quietly mention the word (Alzheimer’s) to others who we meet.”

CARER, USA

“At first I was unable to talk about the disease without getting upset and I felt people thought my husband was stupid or I was a domineering wife. I therefore hid the diagnosis for a few years.”

CARER, UK

Families face many challenges when decided whether to hide the diagnosis from others. The considerations include whether the person diagnosed wants his or her diagnosis discussed, whether the family carers have accepted the diagnosis and how others may react.

“Some family members didn’t want to know about the diagnosis – preferred to think parent was just getting old.”

CARER, AUSTRALIA

“She doesn’t like to talk about it. For the first few months, she was living in a private care home and did not want anyone to know about it. She doesn’t

want non family persons to drive her anywhere in case someone sees her with a caregiver.”

CARER, CANADA

“My father chose to not tell my mother that she had Alzheimer’s. We and the doctor told her she had ‘short term memory issues.’ She was once told she had Alzheimer’s – she went ballistic for about two hours ... and then, mercifully, forgot. My father didn’t tell Mom’s friends of the actual diagnosis ... but they all knew something was wrong.”

CARER, USA

“Because I knew my mother’s social and former professional friends would treat her differently, I concealed the diagnosis. I wanted her to be her for as long as possible.”

CARER, CANADA

“I have alerted neighbors and those that come in contact with her that she is having memory issues but have not come right out and told them she has Alzheimer’s.”

CARER, USA

“We have only told family, pastor, and medical caregivers. He is still active as a musician and doesn’t want the diagnosis to interfere with his playing in public. He hasn’t told old and close friends so that he won’t be treated any differently.”

CARER, USA

“I have a lot of responsibility in my job; I do not want anyone to blame my personal issues on job performance. When I need to let my bosses know (am practice manager [of] large medical group) I will let them know. [I] do not want special treatment.”

CARER, USA

“My wife is very self-conscious about her problem and feels that it makes her less of a person, so, out of respect for her, I do not generally discuss it. However, close friends have picked up on it and asked me, so I have spoken with them confidentially. As a caregiver it is a problem for me to keep this ‘secret’ because it is quickly obvious that all is not well with my wife. It is also obvious that all is not well with me since I am not generally available for any activity that keeps me away from her for more than a couple of hours. In addition, we used to travel extensively and that has come to a complete and obvious halt.”

CARER, USA

To the same question in the Spanish survey, 78% (170) of carers said ‘no’ and 8% (15) said ‘yes’. The themes were slightly different than those in the English survey. There was a feeling that since dementia is not the person’s fault, disclosure is okay. A few people said that disclosing depended on how the person with dementia reacts. The person with dementia is not always aware of his or her own memory issues or does not seem to want to discuss it.

“Only my immediate family know about it. I have kept it hidden from all non-relatives.”

CARER

“It took me a year to accept my mother had Alzheimer’s.”

CARER, SPAIN

“I think everyone should know the state of health of my mom, it helps to make my care more complete since all contribute or bring something in a given time.”

CARER, COLOMBIA

“My father only knows that mom is losing her memory because of her age, but in general, the family doesn’t want to hear anything about Alzheimer’s disease.”

CARER, ARGENTINA

“My mom does not want neighbours and friends of my dad know about it.”

CARER, COSTA RICA

## Being treated differently

To the question **Have you been avoided or treated differently because of the diagnosis?** 50% (862) carers in the English Survey said ‘no’ and 28% (487) said ‘yes’. Of the individuals that said ‘yes’, 165 reported social exclusion as the most frequent thing happening to them and the person they care for. People mentioned not being included in invitations to social outings and family gatherings, that friends have stopped calling and visiting, and that friends and family do not communicate with them any longer.

“People in the retirement community where we live prefer not to sit at a table with us in the dining room.”

CARER, USA

“Long time friends and family no longer call or visit. They have stopped all interaction as though the disease is contagious. They say ‘they can’t bear to see him like this’.”

CARER, USA

“Family members do not want to visit because she isn’t ‘the same’. One has actually said she isn’t their Mom anymore.”

CARER, CANADA

“Some people act as if he’s no longer alive and don’t ask me how he’s doing.”

CARER, CANADA

“Friends have given up inviting me out socially, as I’m always busy with Mum – or too tired to go out!”

CARER, UK

**“Other teenagers did not understand and they chose to leave me because I was sad.”**

CARER, DENMARK

“We aren’t included in ‘couples’ activities that we used to be part of.”

CARER, USA

120 people shared examples of other people’s behaviour changing around them such as people being awkward, or not knowing what to say to the person with dementia. There were also 25 people who reported being treated positively in the narratives. Six carers indicated they had been treated differently at the workplace.

“When we go to church, sometimes people who would have come to the table where we sat no longer do that.”

CARER, USA

**“Some friends are gone and some have become closer.”**

CARER, DENMARK

“People are withdrawing from my husband because they don’t know what to say. However, some family members are becoming more helpful.”

CARER, USA

**“Much less support at work to be able to juggle work and life as compared to others who have children to care for. Work doesn’t ‘forgive’ as easily when you’re a caregiver for a parent.”**

CARER, USA

“When I moved my mother in with me rather than a nursing home my siblings were pissed. I cared for my mother at home until she passed about three weeks ago. When I took early retirement from my job three years ago to provide full-time care, my co-workers echoed my siblings’ opinion that she should be in a nursing home. No one visited much before she was bedridden; and after – no one; save my two sons.”

CARER, USA

In the Spanish survey, 14% (25) of carers indicated ‘yes’ they had been treated differently and 77% (140) indicated ‘no’. Although the number of respondents that provided narratives was only fifteen, almost half (47%) reported social exclusion as the way in which they were treated differently. Other carers reported they did not like seeing the person with dementia treated like a child or looked at differently, that they themselves were treated with pity and family members withdrew from responsibilities.

“The brothers of my mother don’t believe the disease and have broken off the relationship with me.”

CARER, SPAIN

“The family did not take responsibility and the friends were gone.”

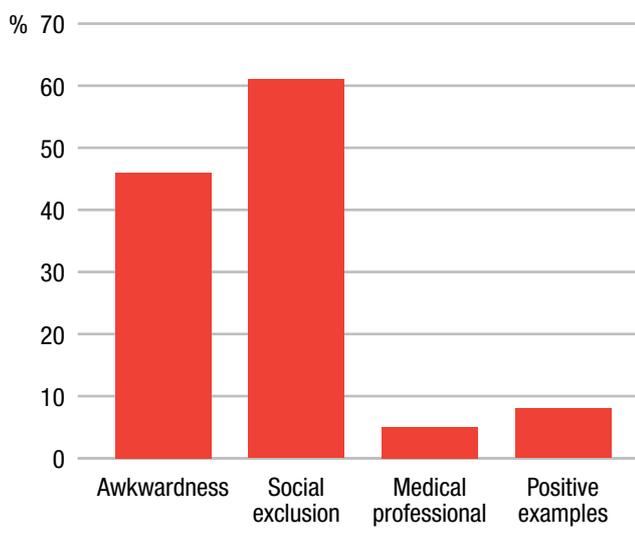
CARER, URUGUAY

“Not avoided. But a different treatment, yes: we cherish her the most.”

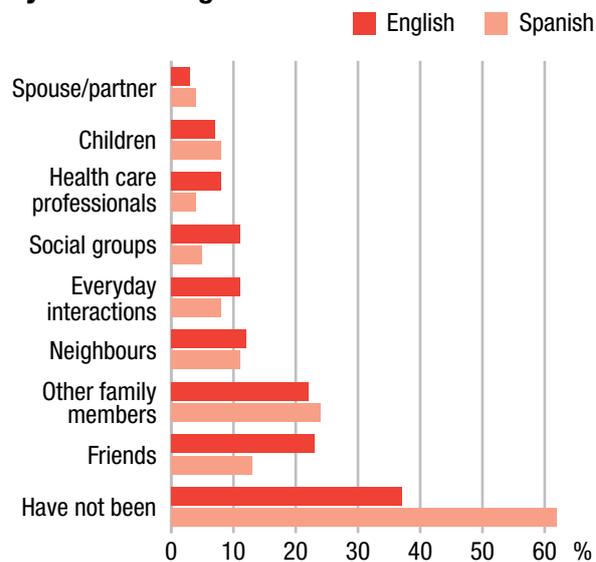
CARER, COSTA RICA

English Survey

**Have you been avoided or treated differently?**



**Have you been avoided or treated differently by the following?**



**Have you been avoided or treated differently by the following?**

In the English survey, among the carers who commented that they have not been treated differently, 66 people explained they have been supported in caring for their relative or friend with dementia. Those that have been avoided they indicated several reasons such as the increased care tasks were too much for some family members (10), feelings that other people have a significant lack of understanding about what caring for someone with dementia is like (88), and some indicated that there is less socializing for themselves and the person with dementia (81). Thirty-three people indicated that stigma was the reason people avoid or treat them differently.

“Some family members felt he should have been in a long term facility because of total care required. A tennis group wanted him to stop playing tennis, others were afraid of him getting hurt or hurting someone.”

CARER, CANADA

“It’s very painful for me, that my mother has been diagnosed with Alzheimer (severe degree), and she was hospitalized in [the] psychiatric system [for] 3 months. I was home from work 3 weeks with depression and unable to take care of my responsibilities. People do not know how to react!”

CARER, DENMARK

“It’s odd because those closest to you who seem to understand will leave you out of an event, thinking you cannot handle it instead of talking to you about it. And then family will put more and more on you and never say ‘thank you’ and threaten to withdraw their help if you react negatively to them in any way. It’s a

lose-lose situation. Only my mother appreciates my help.”

CARER, USA

**“I found it particularly difficult talking to government departments, banks and other institutions as they are unaware how to communicate effectively with us.”**

CARER, UK

“His family was in denial forever it seemed. They blamed me having him on medication for his behaviour. ‘Get him off all that medication and he would be fine’ ... they have told many others. As long as I met all his needs (hygiene, financial affairs, etc. they thought all was well). He was incontinent and they also felt I was seeking attention, by making that statement!”

CARER, CANADA

“At times we were not invited to dinner parties as the person having it thought it would not ‘be fair to my husband to put him through the embarrassment’. Well he was never embarrassed by his illness but other people were.”

CARER, NEW ZEALAND

**“The hardest group to deal with has been my mother’s siblings. At first, they were angry at us for taking control of her finances, and thought we were making some kind of power move for her money. Now that they realize what the disease actually is, it is very awkward. In addition, they are now relying on us to help explain everything/ counsel them ... instead of being able to be there for us, as caregivers. Instead of being the ones we could lean on when things get really hard, we are actually**

**the ones having to be there for them, as they process the reality of the disease.”**

CARER, USA

Reactions regarding health care professionals also came out in the themes of the narratives:

“Health care professionals are the worst; because she had Alzheimer’s disease, many were reluctant to treat her properly for other illnesses. Also nursing staff were ridiculous in that I had to justify my mother’s ‘odd’ behaviours so that she would not be deemed as a ‘bad’ or ‘dangerous’ person.”

CARER, AUSTRALIA

**“Sometimes it feels that GP [general practitioner] and some other health care professionals discard other ailments that arise because of the dementia due to the fact that my father is in a very advanced stage of the disease and because he no longer communicates.”**

CARER, AUSTRALIA

“Sometimes being treated differently is not bad – I have been given great treatment because people know my father has dementia and people try to help with that situation. Dad was kicked out of an assisted living (the dementia ward) because he was aggressive. I would have thought they would have known how to handle someone with dementia since it was a dementia ward. He was also kicked out of a dementia adult day center (connected with an assisted living) because ‘he needed too much attention.’ It is disheartening to me that places that call themselves dementia wards are not able to handle dementia patients that aren’t in the severe stages of just sitting around and looking at one another.”

CARER, USA

In the Spanish survey, 68% (102) of carers reported they had not been treated differently by specific individuals. Of those that had, they listed other family members as the highest percentage (24%), followed by friends (13%) and neighbours (11%). Although there were only 30 narratives, they included comments about receiving little or no help for the increased care tasks, a lack of understanding, the person with dementia being treated differently and a case of abuse by health care professionals. Only 4 people had described being supported by others.

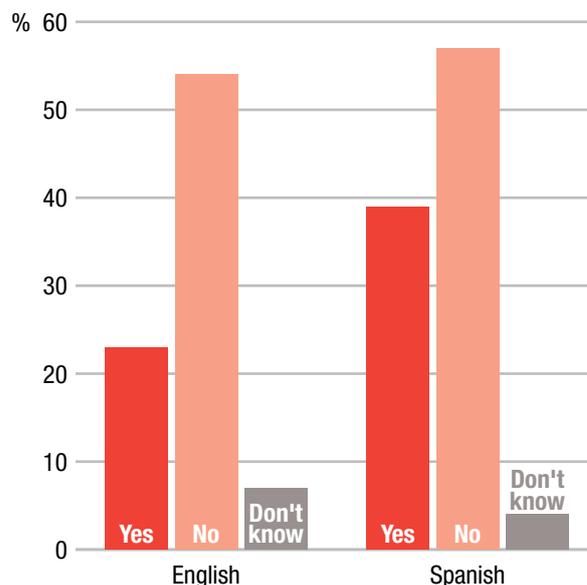
“All the people in my environment have treated me very well; I have never been avoided or treated in a different way.”

CARER, EL SALVADOR

“Neighbours and some family members believed that as you cannot [take care of yourself] you have to die.”

CARER, SPAIN

### Have you stopped yourself from having a close relationship with anyone since the diagnosis?



“All people left my mom when she got ill. They did not want to see how she deteriorated. In the year nobody called me to see how she was.”

CARER, ARGENTINA

“The different treatment has been really positive. The closest people have been very outstanding to help in everything they can. And also taking into account that my husband is in the early stages.”

CARER, COLOMBIA

“My friends only regretted it and I did not see them again, maybe I withdraw from them, by the priority of arriving home. [...] Not [...] even a call from them ... in particular my mother’s friends from the Church thought of my mother as ‘mad’ they did not visit her ... Indeed, I felt isolated, little social support ... today I am building my network of friends who are related to dementia.”

CARER, VENEZUELA

### Have you stopped yourself from having a close relationship with anyone since the diagnosis?

In the English survey, 23% (388) of carers indicated they have stopped themselves from having close relationships; however 54% (927) had not stopped themselves. We still have much to learn from carers who are isolated and struggling to maintain relationships. In narratives, 171 carers indicated they do not have time or it is too difficult to maintain relationships due to the responsibility of caring for the person with dementia continuing the theme of isolation and exclusion from society of both carers and people with dementia. In addition, the theme of lack of understanding was pervasive as 55 carers indicated people just do not understand what it takes to care for someone with dementia.

"As a caregiver, it is difficult to maintain outside relationships with friends due to caregiving demands and supervision of the person with dementia. Also your world centers around caring for your spouse and you lose your interest in broader issues to discuss with others. Caring for a person with dementia becomes very insular and isolating. You eventually only talk about life in the dementia world because it is so consuming. Friends/family not living in that world may be sympathetic but don't want to hear about the constant challenges of caregiving and the losses associated with progressive dementia."

CARER, USA

**"I have not stopped myself from having close relationships purposely, but definitely have lost friendships just because I have been at times too overwhelmed or depressed to keep in touch with old friends."**

CARER, USA

"I do not hide or 'sugar coat' anything for anyone. I do not attend functions or go for coffee etc. with people I used to know since I have found they do not want to hear the truth and are very uncomfortable being around me. At this point I really crave someone to talk to and be close to. My wife is not able to carry a conversation about anything and has lost any type of close contact. I think I need a hug :-)"

CARER, CANADA

**"Since I need to be with my spouse most of the time I am not working, I no longer have the time for outside relationships, which is unfortunate since I need them more than ever."**

CARER, USA

"I do not have time to talk on the phone, much less go out with someone. I am a part time college student but may have to drop my classes because I cannot leave my mom alone. My plans of resuming a normal life after my twins graduated from high school have not worked out like I planned. I am confined to these four walls, doctor offices and hospitals. No income and very isolated. I wish I had someone in my life. Maybe I would not be so overwhelmed and so alone ... invisible."

CARER, USA

"Nobody wants to be burdened with my problems in caring for my spouse with dementia. Besides, they do not understand, and then they feel they have to make suggestions, which are TOTALLY unrealistic! Makes me furious and cry."

CARER, USA

In the Spanish survey, 39% (67) of carers have stopped themselves from close relationships; 57% (99) have not. Similar to the English survey, Spanish-speaking carers indicated they have no time or it is too difficult to maintain relationships, they have lost friends, or they

**stopped a relationship with someone who has treated them unkindly.**

"From the moment of diagnosis and also because I look after my mother, I don't have time to maintain relations and I had to stop doing many activities."

CARER, SPAIN

"In my case for not having help; I had to move away from friendships and groups such as going to church (Catholic practitioner) and from my work (I'm a teacher); the level of [...] care that my mom requires takes a lot of my time; although [...] she has been diagnosed not long ago (6 months) she has periods of severe agitation and lack of control, I have to sort and manage her medicines, unfortunately in this area where we live there is no assistance in occupational therapy so I've had [...] to investigate and put into practice what I have been learning."

CARER, VENEZUELA

"As a family caregiver, I have no time to interact with friends and friends all have withdrawn because I devote myself more to take care of my mother, although there is a professional carer that takes my turn when I go to work."

CARER, CHILE

"I think that the presence of my mother in my house at the beginning of the diagnosis was not good for my relationship with my husband."

CARER, USA

"I think that my life turned to support my parents and to cope with the illness of my mom and my parents that made withdraw from all."

CARER, COSTA RICA

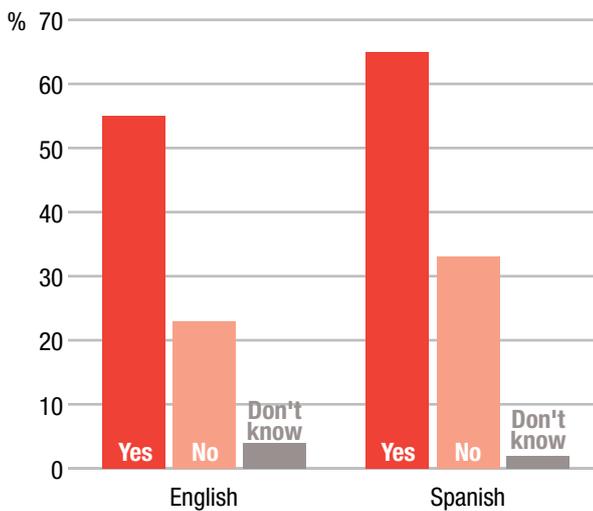
"I believe that there are people [friends] that go away because as caregivers, we hardly go out. But those who really matter (our children and some relatives) are there. I always say that the relationship close with God [...] is the most important."

CARER, VENEZUELA

## **Friendships with people not connected and connected to dementia**

In the English survey, 43% (732) of carers report making friends with people who are not connected with dementia in some way since the diagnosis, for example, they do not have dementia or do not care for people with dementia; 34% (578) have not made friends. Most cite a support system through their current friends, with neighbours and in their current social networks. In addition, many people report making friends through their faith organisation or volunteering. A couple of carers indicated they are afraid to make new friends for fear of rejection.

**Have you made friends with people affiliated with dementia?**



In the Spanish survey, 51% (85) of carers reported making friends not connected to dementia; 46% (77) reported not making friends. Carers indicated that it was important to maintain their current relationships and that people who are comfortable with older people tend to be more sympathetic to their situation.

**Friendships with people affiliated with dementia**

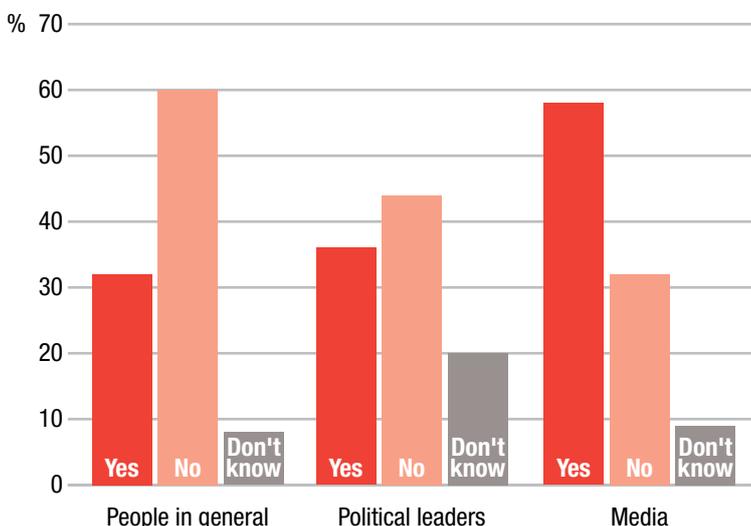
In the English survey, the majority of carers (55% or 943) have made friends with people who are affiliated with dementia in some way, meaning other carers or persons with dementia. Only 23% (409) have not made new friends. Carers describe locations where it is easier to meet friends in the same boat, so to speak, such as meeting other carers when they visit their relative in the care home or making friends with the other residents when they visit their own relative. Over 130 carers reported making new friends with other carers and people with dementia through Alzheimer’s organisations, support groups and online. Twenty-three people indicated they have become friendly with professionals who work in the dementia field.

In the Spanish survey, 65% (112) of carers indicated they have made friends with people who are connected to dementia; 33% (58) had not. The themes in the narratives are similar to the English survey with people meeting other carers through organisations or support groups. A number of people described online social networking, such as Facebook, as being a way to connect with new friends who also care for their relatives with dementia.

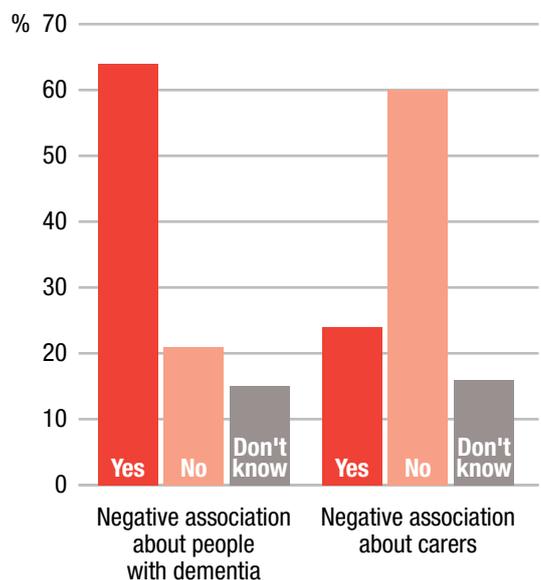
**Understanding dementia**

**Do people/political leaders/media understand dementia in your country?** In the English survey, the majority of carers (60%, 850) felt that people do not understand dementia within their respective countries; 32% (460) of carers reported people do understand

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



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



dementia. Among the 344 written narratives, 41% (142) of carers reported limited awareness amongst the general population and 43% (147) reported a great misunderstanding of dementia, Alzheimer's and other related illnesses. Carers felt people have some knowledge or some awareness, but felt it was not enough or sometime not accurate and based on stigmatic beliefs of what dementia is. A few carers said they wanted ADI to know they feel organisations are trying hard to change this.

With respect to awareness amongst political leaders, 44% (626) of carers in the English survey felt political leaders are not aware of dementia; 36% (509) indicated they thought political leaders are aware. In the 299 narratives, 71 carers indicated that awareness of political leaders is not enough, with 38 people reporting a lack of understanding of the real issues faced by carers and people with dementia. Carers mentioned that political leaders may be aware of the growing numbers, but not of the financial toll the disease imparts on families individually. They also felt that if political leaders did have knowledge, it was either due to a personal experience in the leaders' own families or important to them during an election campaign. Twenty-seven carers felt political leaders just do not care about the issue.

"Among some, but not enough of them! We still do not have a national Alzheimer strategy in Canada and we probably would have one if enough political leaders knew more about dementia."

CARER, CANADA

"They don't take actions. They talk about respect and help but I expect more."

CARER, ARUBA

**"Yes, but I question how serious they are in addressing the issues. In Australia, we have an aging population so this is seen as an opportunity to make money by placing these individuals into care, often requiring the family to sell the family home."**

CARER, AUSTRALIA

"There is some awareness but the politicians certainly haven't addressed the issue in any in-depth way. We're on our own."

CARER, USA

"In America, most of the political leaders are wealthy and have access to great insurance and medical benefits so I feel that their family members with dementia/Alzheimer's are undoubtedly in state-of-the-art assisted living facilities and/or have skilled home caregivers."

CARER, USA

"Alzheimer's disease is still the disease we sweep under the carpet."

CARER, USA

In the English survey, carers report more awareness amongst the media – 58% (828) people said 'yes' to this question; 32% (460) said 'no'. In the 306 responses to the narratives, 45 carers indicated they recognize that media awareness is growing. However, many carers (41) reported that they still see a great misunderstanding of the facts of dementia and its impact on families. Thirty-nine people felt much media attention is either focused solely on drug research or is still negatively represents dementia. Twenty-five people noted the celebrity faces that have helped normalize dementia such as Ronald Reagan, and Pat Summitt (a famous basketball coach) in the US and Terry Pratchett in the UK.

**"There is starting to be more awareness but we are a long ways away from where we need to be."**

CARER, CANADA

"There is awareness, but not enough. I think it is getting better. When my husband was diagnosed almost 9 years ago with early onset Alzheimer's, I called elder care and several other organisations and they wouldn't even talk to me because he was younger than 60 years old. It was very frustrating. The Alzheimer's Association where we lived at that time also had no programs for early onset Alzheimer's. It was a very lonely place to be for a caregiver. I still get the comment that 'He doesn't look like he has Alzheimer's'. How is one with Alzheimer's supposed to look?"

CARER, USA

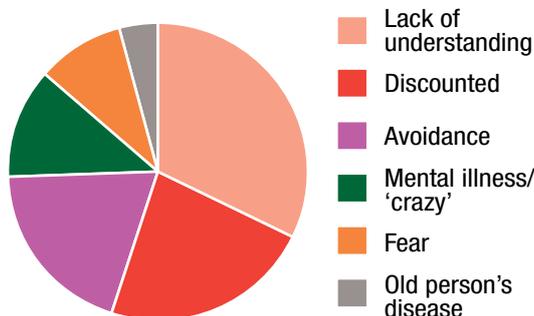
"There seems to be more coverage of Alzheimer's and dementia in the media but I don't know if it translates to more awareness, rather it seems that they put a story in the news when there is a major conference or announcement of a celebrity being diagnosed."

CARER, USA

## Stigma about people with dementia

**Do you think there are negative associations (i.e. stigma) about people who have dementia in the country where you live?** Even though media attention is growing, the majority of carers (64% or 892) still recognize a negative association about people with dementia within in their respective countries; 21% (296) felt there was not a negative association and 15% (212) were not sure. In the 324 narrative responses, 99 people felt a lack of understanding, 70 carers shared examples of the person with dementia being discounted by being made fun of, being ignored even though present, treated like a child or talked over, and 60 carers indicated avoidance as another way in which people demonstrated negativity towards a person with dementia. Thirty-seven people commented that a person with dementia is seen as having a mental illness or 'crazy'.

## Negative associations about people with dementia



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

CARER, AUSTRALIA

“We still hear about people with dementia whose friends drop away because of fear or misunderstandings about dementia. They are awkward or uncomfortable about how to act around the person or his/her spouse, so they reduce their social interactions. My mother, however, was fortunate to have solid friends, who were all strong in their religious beliefs, who stayed with her and Dad during the entire journey from diagnosis until she entered long-term care.”

CARER, CANADA

“There is some stigma here in so far as it is not easy to take the person anywhere ... Facilities are limited – scarcity of disabled toilets; transport is difficult.”

CARER, AUSTRALIA

“There is an apathy. People just don't seem to be interested in people with dementia. They are not sufficiently educated in the dementias.”

CARER, AUSTRALIA

“Absolutely. They are no longer regarded as human beings especially by nursing and medical staff as they are seeing a 'diminished' state of the person who I love. In other words, they do not see the person that I do as I have the history with him and not them.”

CARER, AUSTRALIA

“I found many health care personnel – especially in ER [emergency room] and in patient units have little understanding or respect for older adults – especially those with dementia. They try to chemically or physically restrain them instead of understanding the need to walk around. They 'medicalize' the condition instead of looking at ways of supporting the patient's independence and autonomy and sense of self.”

CARER, CANADA

“When my husband does 'odd' things when in public, people look at him strangely. For example, in the grocery store he didn't go through the check-out as directed and others were waiting. The person behind me was letting out audible sighs. I turned to her and apologized, saying that my husband has Alzheimer's. Her attitude, and the check-out person's, changed completely. I used the word 'Alzheimer' because it seems to be more easily understood than 'Dementia'.”

CARER, CANADA

“I think a lot of people believe that people with dementia cannot function anymore in our society. [Dementia] is however a gradual process, and especially in the beginning, my mother was still able to do things and to understand what people said about her to us.”

CARER, NETHERLANDS

## Stigma about carers

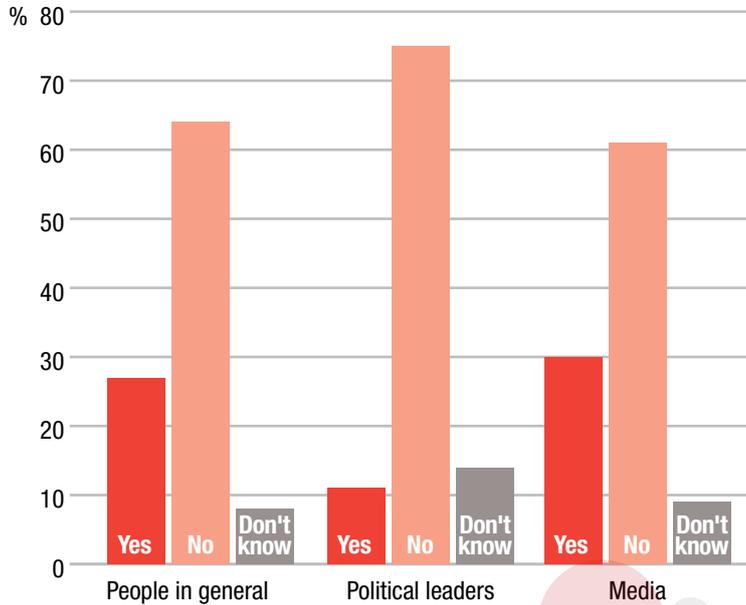
**Do you think there are negative associations about people who care for people with dementia in the country where you live?** In the English survey, 60% (842) of carers indicated they did not think there were negative associations about carers in their respective countries. Of the 24% (336) that did, their narratives indicated that they too feel avoided or discounted in addition to the person with dementia. Thirteen carers shared examples of hostile reactions they receive from others including being treated negatively in the workplace. They feel there is a lack of understanding and appreciation about the time and costs associated with caring for a person with dementia. Not just financial costs, but the expectation that giving up their own lives is an acceptable expense in society. A theme of martyrdom was used or implied 19 times as a way that people respect the carer's sacrifices, but some carers indicated it was not their desire to be martyred. Other examples include siblings and others making the carers feel like they were making excuses for themselves or the person with dementia by not participating in previous activities. Being treated with pity was a common theme, as was unsolicited advice from family, friends and strangers. The most common unsolicited advice reported by the carers in the survey was to place the person with dementia in a care home. Requests of better support for carers were also a theme.

**Do people/political leaders/media understand dementia in your country?** In the Spanish survey, 64% (113) of carers indicated that people do not understand dementia in their respective countries; 27% (48) said that people do understand. Similar to the English survey, carers indicated there is lack of understanding of the depth of taking care of a person with dementia.

“There is no awareness, or understanding of the population and the community in general, because

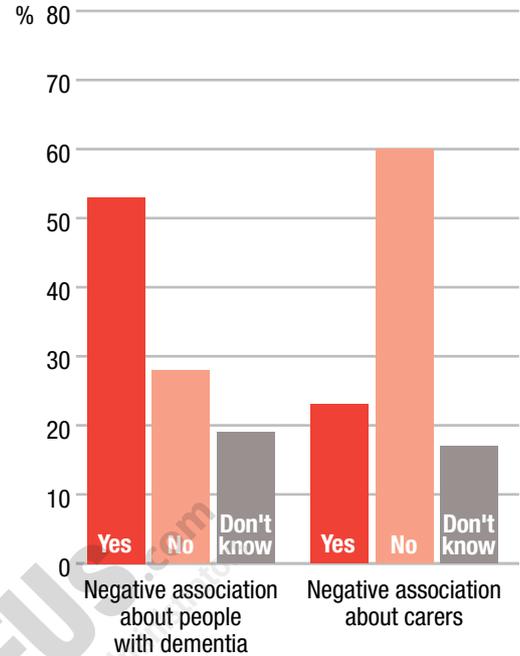
Spanish survey

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



Spanish survey

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



there are no programs by State or culture for the healthy elderly with dementia at a population level.”

CARER, VENEZUELA

“People don’t know much of disease until their family suffers from it.”

CARER, COSTA RICA

“The general concept of dementia that we have is that a person who has some type of dementia is crazy.”

CARER, COSTA RICA

“Not as it should be; not only in my country, around the world, I think that there is much ignorance and shame. Especially by relating dementia with madness.”

CARER, VENEZUELA

With respect to awareness amongst political leaders, a greater number of carers (75% or 132) in the Spanish survey indicated that political leaders in their respective countries are not aware of dementia. They reported that there is no aid or financial assistance for people in their country and that political leaders have little, if any, understanding about the disease. If they have knowledge, a lack of action is felt. Also similar to the English survey, carers pointed out that if a political candidate has personal experience with dementia in the family, he or she is more likely to be aware.

“Except in cases that they have the experience of a family member. It is not considered as a public health problem.”

CARER, URUGUAY

“Not yet, but I think that they will be paying more attention to this issue soon.”

CARER, CHILE

“I have personally requested economic support and other things, and for my Grandma to receive such support she needs to be completely abandoned and neglected by us to receive this assistance!! As I said at the beginning for many years I cover all the needs of my grandmother, from diapers, medical, etc. Right now I have a difficult situation because I have no work and there is no one who will help one in this aspect.”

CARER, COSTA RICA

A difference between the English survey and the Spanish survey is awareness amongst the media – 61% (107) of carers felt that the media does not have an awareness of dementia and only 30% (53) felt the media did. Of those that did, they felt it was not enough or limited and that Alzheimer’s organisations encouraged what media existed. Some carers provided examples of the media’s lack of understanding and their inappropriate use of the word ‘crazy’ when referring to people with dementia.

“The media is aware of what is dementia and there has been even a program that focused on the

subject but it is in general an issue of little interest, rather the topic is indifferent to the media both TV and press as a radio.”

CARER

“As I said before, they always say that [people with dementia] are crazy, that they are people who are losing their ability in their brain.”

CARER, COLOMBIA

The majority (53% or 93) of carers felt there are negative associations about persons with dementia in their respective countries; 28% (49) did not feel this way and 20% (34) were unsure. Of the 49 narratives, 14 cited examples of others thinking the person with dementia is crazy or has a mental illness or that the person is drunk. Eleven carers said people with dementia are avoided, abandoned or invisible in their society. Ten carers said people with dementia are mocked, or seen to no longer have function or treated like children. Overall, carers identify a lack of understanding about what dementia is, and what is involved in caring for someone with dementia and people are hidden away for fear of bringing shame to the family.

In the Spanish survey, 60% (105) of carers indicated there is not negative association about carers in their respective countries; 23% (41) indicated there is and 17% said they were unsure. Similar to the English survey themes include avoidance, pity, being discounted as the carer, unsolicited advice and accused of making excuses.

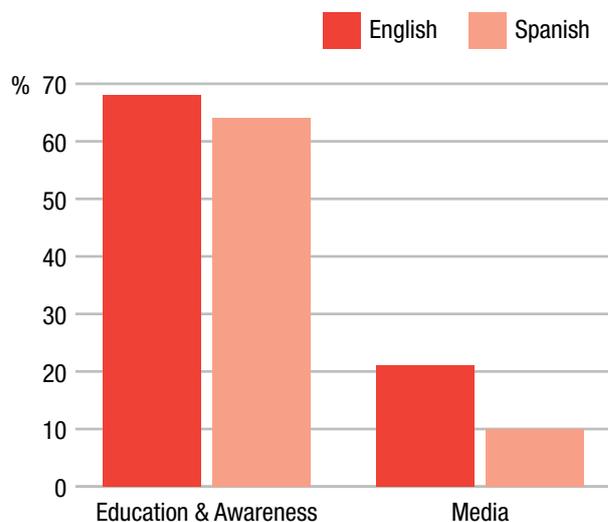
Carers sensed that people in general feel that they are worthy of recognition as many devote themselves to the person with dementia.

## Coping with stigma

To the question **Do you have personal skills and abilities to cope with stigma?** 67% (928) of carers in the English survey said yes, 14% (189) said no and 19% (269) said they did not know. In the narratives, carers described that it's a skill that develops over time, having friends helps them get through, and people indicated turning to their faith for support or that their love for the person with dementia gets them through. Many carers in this study reported having either previous personal experience by caring for other family members or professional qualifications that augment their knowledge about the disease and help them cope. Deflection was common as well. Carers reported simply not caring what other people think. Another key theme was that of 'good days and bad days'.

In the Spanish survey, 53% (90) of carers reported they have skills and abilities to cope with stigma; 25% (42) did not and 22% (37) were unsure. Common themes included education about the disease helps, and one must have resilience and patience. Similar to the English survey, faith is important and love for the person with dementia. Some carers reported that the person with dementia did not choose to have this disease

## What do you think can be done to reduce stigma?



and therefore, it is not their fault. For those that did not feel they have abilities, depression was cited as a consequence, and sought counselling.

## Reducing stigma

There were 945 responses to the question **What do you think can be done to reduce stigma in your country?** Carers in the English survey reported education, information and awareness activities (648) were the most important task for countries.

“Continue educational efforts about dementia and call for a national strategy in the same way that cancer is now getting much more financial support and education than it used to 20 years ago.”

CARER, CANADA

“More information, more support from the government and the media.”

CARER, ARUBA

**“Raising awareness about Alzheimer’s disease. Involving and showing activities of people with dementia. Helping caregivers to accept the new conditions and that Alzheimer’s disease is a disease.”**

CARER, IRAN

“We can educate general public, [and] students by conducting awareness programmes about dementia and giving training to the caregivers.”

CARER, INDIA

**“More opportunities for young people to meet older persons with dementia in settings that encourage evocation of their strengths ... Public education programs could do more in the way of teaching the general public how to**

**talk with people with dementia, how to find their strengths, what obstacles to be aware of. Many people are bewildered by how to respond to people who do not talk 'normally' and so may shy away from trying to engage them."**

CARER, USA

"More education and awareness for the public of what this disease is and how to accept and deal with it. My husband is met with stares and looks when he is in public and displays symptoms, for the general public has no understanding. I have heard 'what a weirdo', instead of knowing he can't help his behaviour."

CARER, USA

"Better awareness by the general public. Focus on the positives of what the person can do – there is a life after dementia diagnosis!"

CARER, AUSTRALIA

"Improved knowledge and understanding of dementia and improved support programs for people affected by it. It is likely that dementia will affect more people with an aging population, but it appears that little is being done to address the obvious needs."

CARER, USA

"A free workplace training package that would sensitize people to the plight of dementia, that could be delivered in-house by all organizations. It would have to be free as most organizations wouldn't pay as they don't see it as a priority."

CARER, CANADA

"Mandatory education at all levels of education. A couple of classes/short films/discussions each year. And as more families consolidate to care for older family members, applicable problem-solving courses are essential ... creative problem solving that will serve not only those caring for those with dementia, but ripple out into careers and life in general. I believe

in the power of creative problem-solving, starting early-on."

CARER, USA

**"Awareness of the disease and helping people understand the warning signs. Assisting those with dementia to seek out about their experience to enlighten others. Educating health care professionals about the diagnosis and the benefits of giving the diagnosis. Acknowledging Alzheimer's disease and other dementias as chronic illnesses. Formally supporting family caregivers in their caregiving roles with policies and financial support."**

CARER, CANADA

Media was also seen to have an impact by 21% (201). Many carers reported having celebrities visible is helping the cause. Survey respondents also suggested that government and organisations have a role in reducing stigma 10% (96), in addition to policy 4% (37) and research agendas 3% (32). Over 20 people shared specifically they feel that financial support is seen as a commitment to helping families care for people with dementia at home versus 'sending people away' to nursing homes because that is where the majority of funds currently provide assistance. Thirty-nine people reported that reducing stigma is unnecessary.

"More people need to be informed of what dementia is and how it affects people. Some people may not even know that young people are also affected. There could also be more media awareness."

CARER, AUSTRALIA

"Education of the general population and having positive role models portrayed in the media."

CARER, CANADA

"More information in media, for example, commercials that talk about dementia and the effects, the effects on families, emphasizing its a disease."

CARER, CANADA

## Dementia, poverty and stigma

A number of people mentioned in the survey that they face serious financial problems because they have lost their jobs due to having dementia or caring for a family member. From the population based research done by the 10/66 Dementia Research Group, we know that 6-30% of carers cut back or cease paid work in order to care\*. Financially supporting carers can give them status and recognition for their role, as well as helping their financial situation. Reducing stigma could lead to greater sympathy for people with dementia and their carers and understanding that they should be valued by society.

There may be a parallel with the situation of people with disabilities, at least in higher income countries, who campaigned for inclusion in society and were given some financial support. This happened as societies became more open to including people with disabilities. Some European countries, including the Netherlands, UK and Germany, now offer some financial support to dementia carers for the time they spend in caring for their loved ones.

In the Spanish survey, 115 carers responded. The largest number of people (74) also said education, information and awareness initiatives are the most important to reducing stigma. Similar to the English survey, carers mentioned providing education early in schools and putting education in health centres so people see it during check-ups. There was also a theme of having more services available outside of major cities where it is possible stigma could be more prominent than in larger cities. Fourteen people reported assistance with the costs of caring for someone with dementia from governments would reduce stigma as the investment of government money would legitimize the cause. 11 carers wanted to specifically see the creation of respite or support centres where people with dementia could go during the day so families can work and care for their loved one. Twelve individuals felt media initiatives would be helpful.

“Inform, deliver talks at all levels: families, students, health workers, reach the media, authorities, start working with children.”  
CARER, MEXICO

“Promote healthy ageing, have a vision of positive experience and for health professionals and authorities to prepare better.”  
CARER, VENEZUELA

“To start support groups, where participants can benefit from the experiences of others and focus on that this is a disease like any other.”  
CARER, PANAMA

“More education in the primary and secondary school population.”  
CARER, COSTA RICA

“To inform about the symptoms of the illness and not to allow trivialisation of the illness through things like stupid comments or using reference to illness to insult someone.”  
CARER, MEXICO

“Communicate. Raise awareness. Educate. To legislate. Train (the medical profession should be trained to advise and support family members of the patient). Economic aid to solve the cares of the patient. Flexibility on the job (schedules, licenses, etc.), family caregiver for the patients.”  
CARER, URUGUAY

“Designate more financial resources from the Government to the training of personnel in the treatment of patients with Alzheimer’s disease, as well as specific support assistance centres.”  
CARER, SPAIN

“First of all create a policy regarding this disease and especially support to families involved with patients.”  
CARER, CHILE

“Talk more about it, programs on television, make informative campaigns.”  
CARER, SPAIN

“I don’t think it’s something easy. It is important [...] [to educate] the population about what is this disease and its variant symptoms from one moment to another, [what] being with people [with dementia] [...], from one place to another, [or one] situation to another [is like]. Only with information that reaches the entire population can [stigma] be reduced and I think we need a generational change.”  
CARER, SPAIN

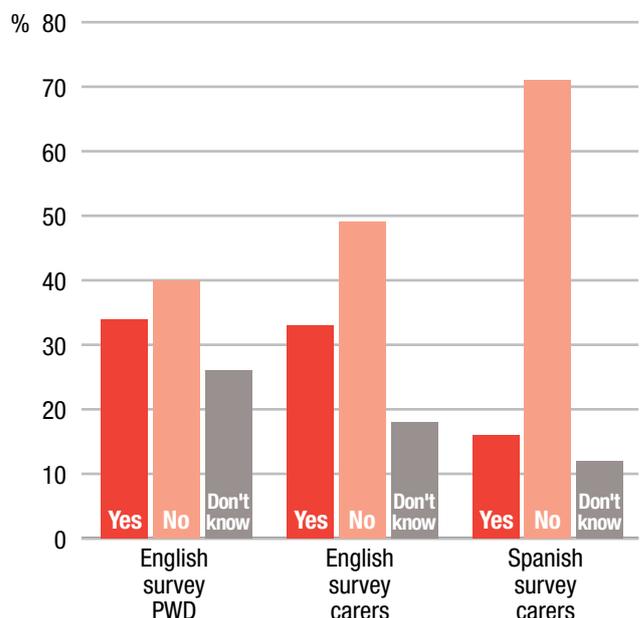
“Provide abundant information on the symptoms of the disease and its development, because in some cases people who are in the early stages can be productive and functional. The information helps to defeat the stigma.”  
CARER, PUERTO RICO

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

### Including people with dementia in everyday life

In the English survey, the majority of carer respondents (660, 49%) felt people with dementia are not included in everyday life, while 33% (439) do feel people with dementia are included. Key themes that were identified from 294 narrative responses included the stages of dementia being an indicator of how included someone

#### Are people with dementia included in everyday life?



with dementia could be (64) and that the family is mostly responsible for ensuring the participation of the person with dementia in society (64). Fifty-four individuals shared concerns about access issues such as lack of transportation, and living in rural areas without services and 49 carers referred to stigma as a barrier to everyday participation.

“To some degree – could be more if more activities were dementia friendly – technology can be helpful here. In my county, the office for aging distributes GPS bracelets, allowing people to live in the community longer without fear of getting lost.”

CARER, USA

“The invitations and facilities are just not available.”

CARER, AUSTRALIA

“Many carers I’ve met describe how friends stop visiting when their spouse acquires dementia. My parent’s friends have tried to stay in touch but they are all very old now or dead so his social circle has reduced and it’s almost impossible for him to form new friendships due to features of the illness such as short term memory loss. I take him out weekly and some people in the shops remember him from when he was well and still speak with him but others are finding it difficult to cope with things like accommodating his wheelchair or being resilient with his awkward behaviours. Some places are beautiful though and seat us where it’s nice but also won’t bother other customers – this attitude enables us to have nice outings still.”

CARER, AUSTRALIA

“Good question. I think that many caregivers are secluded at home, fearful of what the general public might think.”

CARER, CANADA

“With more and more transactions/interactions occurring on computers and using pin cards for payments, people with dementia cannot function. My mom cannot pay with a credit card or debit card (can’t understand the process or pin codes), she can’t count cash, she drives little (and will soon stop) so she’s isolated unless her family helps her. Purchasing groceries and meal preparation is difficult making proper nutrition a challenge. She can’t tell time so has trouble knowing when to get up, when to be ready for an appointment, etc. without a lot of coaching. She has essentially lost her independence in a short time and she’s not even a severe case.”

CARER, CANADA

“People are placed in nursing homes generally. It is harder and harder for families to afford taking care of family members with dementia while trying to work and provide for their families.”

CARER, USA

**“It is so hard to take out someone with Alzheimer’s into public. It is overwhelming for the person suffering from the disease, and people do not want to slow down and help/talk to people with Alzheimer’s.”**

CARER, USA

“In nursing home facilities, these patients are left to sit in hallways or in their rooms. They need programs and places they can be brought to during the day to assist families while they are working or at school. Personally, we don’t trust the state assistance available.”

CARER, USA

“It depends on the skill set of the people around you and who you surround yourself with. Family members who cannot afford engagement activities are either stressed, overwhelmed, or cannot find the time to provide their loved one services. Money is a factor as well.”

CARER, USA

“In some ways, not in others. For example, some church congregations are willing to accommodate the person with dementia, whose behavior does not impact others during a service. Others are not.”

CARER, USA

“They lose friends with their behaviours and carers often don’t share what is going on on a day to day basis for fear of being judged for how they handle the stress or fear of losing friends, or because they are depressed and have burnout.”

CARER, CANADA

“They are neither included or excluded. They suffer in silence. Their families suffer in silence. There seems to be an ‘out of sight, out of mind’ mentality in this country toward those who have dementia and their caregivers.”

CARER, USA

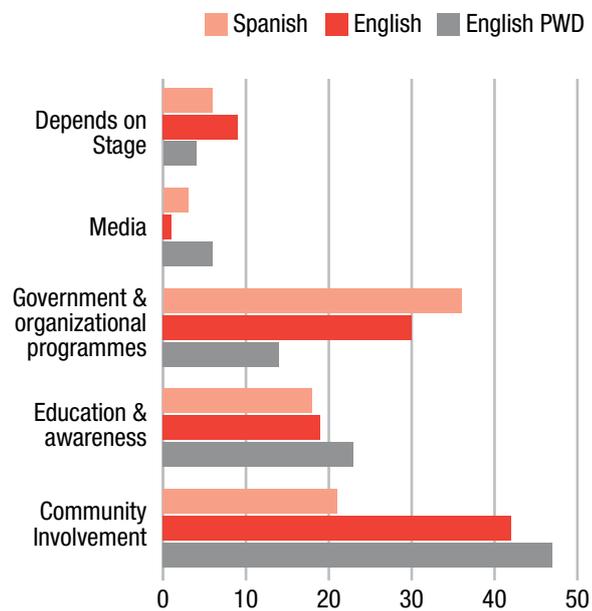
In the Spanish survey, 71% (118) carers reported that people with dementia are not included in everyday life, while 16% felt that they are. Themes from the narratives were similar to those from the English survey. Some carers said stigma remains the barrier that prevents people with dementia from being a part of society. Others commented about the stage of the illness being a barrier and lack of access to services or resources to enable the person to live a more integrated life. Family assistance was also cited as the primary means by which the person with dementia would be able to be included.

“Lack of resources. There are many architectural barriers.”

CARER, SPAIN

“When on rare occasions any of his other sons visit my mom, when talking to her, they do not address

## How can people with dementia be included in everyday life?



her, they don't know what to do, they do not include her, as if she does not exist."

CARER, CHILE

"They are segregated from society."

CARER, MEXICO

"If it is in the primary stage or second, you can, but then it is no longer possible."

CARER, COSTA RICA

## How to include people with dementia in everyday life

In the English survey, there were 752 responses to the question **How can people with dementia be included in everyday life?** Community involvement or changes to the culture were mentioned by 315 carers as ways to include people with dementia in everyday life. Government or organisational programmes were suggested by 227 individuals and education and awareness programmes cited by 140. Sixty-five people noted that they did not think this was possible due to the severity of a person's condition.

**"The government needs to appropriate resources for local Alzheimer's associations to organize events just for Alzheimer's disease patients who live with their families. The current practices to appropriate resources for the general elderly population do not work for us."**

CARER, HONG KONG SAR CHINA

"More awareness about dementia, such as educating people to talk TO someone in the room who has dementia, rather than ABOUT them. Again, education is key to increasing people's comfort levels with persons who have dementia."

CARER, CANADA

"Age friendly environment/culture and dementia friendly environment/culture."

CARER, EGYPT

"As long as possible keep them busy and active in household chores and seeing friends."

CARER, AUSTRALIA

"The government and public transportation companies act as a leading role to build more public access for the disabled and elder people who need walking aids (including regular appraisals and maintenance). Education – starting from primary school."

CARER, HONG KONG SAR CHINA

"Special programs designed to consider where the patients are and to encourage creative activities."

CARER, USA

**"Fund more family carers so the dementia sufferer is more comfortable being included because of the increased confidence provided by the family carer."**

CARER, AUSTRALIA

"By inviting them to cultural and social programs and educating care givers and care takers."

CARER, INDIA

**"There needs to be a feeling of compassion instilled in the community ... NOT PITY."**

CARER, AUSTRALIA

"They can be taken out for a drive, to the shops, to a plant nursery, for a walk. Even though they have dementia and they forget what they have done they can still enjoy outings."

CARER, AUSTRALIA

**"Provide more help for the caregivers in their own home."**

CARER, CANADA

"Making special accommodations for people with dementia ... start with public awareness, then build on that with special measures at public events. I would love to take my Mom for 'part' of the Royal Canadian Mounted Police musical ride, but it's just such an ordeal with parking and seating, not to mention the cost. Everything I do with her costs double when you include my cost. Entertaining my mother is incredibly expensive and I don't want to just sit around and visit all the time ... she does that 24/7 at the nursing home."

CARER, CANADA

“Unfortunately you need money to get a taste of everyday life. As money becomes scarce and savings etc. dry up your everyday life slips away. Financial stability would allow more interaction in public life.”

CARER, CANADA

**“Workplaces could continue to employ people in some capacity with diminished responsibility rather than people becoming unemployed the moment they get a diagnosis.”**

CARER, AUSTRALIA

**“Look and treat them like normal people. Allow them to at least try before you tell them that they can’t do anything.”**

CARER, USA

Themes were similar in the Spanish survey. Of the 107 carers that answered this question, 39 indicated government or organisational support is needed, 23 reported that community involvement or a culture change would help people become more integrated and 18 carers said that people should live their lives and not be prevented from participating in everyday life. Other carers mentioned that help for families should be a priority and that the lack of resources, particularly financial is a barrier to allowing people with dementia to participate in everyday life more fully.

**“Starting with recreational programmes, cognitive stimulation programmes and also social groups.”**

CARER, MEXICO

**“Programs of inclusion, several sectors: Government, churches, health institutions.”**

CARER, EL SALVADOR

“To do and have daily home centres, to train carers and support the family, including our relatives with dementia to events, trips ... ”

CARER, VENEZUELA

“Through spaces and groups with greater understanding and education that enables them to play in what they can do.”

CARER, COSTA RICA

“They have no place in this selfish and consumer society.”

CARER, SPAIN

“To go to these places to have fun as doing exercises, crafts or simply talk. Here the cost of these places is very high.”

CARER, COSTA RICA

“Through more medical resources, social plans and integration of these families with economic and psychological support towards the same.”

CARER, ARGENTINA

“That there would be more therapies and more official centres for them not private, because not everyone can afford paid centres. In this manner they could maintain themselves more actively for a longer time.”

CARER, SPAIN

“Use the experience of life they have had to share with children and young people in social programs.”

CARER, PUERTO RICO

“Establishing support centres, where you can practise activities with people who interact with them and do not feel excluded or disabled from the rest.”

CARER, CHILE

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## What did we learn from carers in the survey?

Carers want and need help and support with taking care of the person with dementia – from other family members, from friends, and from society.

Being a carer is isolating due to the 24 hour responsibilities of caring for the person with dementia. Family and friends need to take the initiative to assist the

carer in successfully maintaining relationships with them.

Programmes and supports are expensive. Carers have little time and few financial resources to utilise what resources do exist to help the person with dementia stay integrated in society.

Carers are often criticised for the quality of care they provide;

their lack of engagement in previous activities and the time they give to the person with dementia is underestimated and underappreciated. Better understanding of what carers require to maintain their employment, their mental health and their social networks is needed.



## Mind games – smoke and mirrors

*Lynda A Hogg*

My name is Lynda Hogg and I was diagnosed with Alzheimer's disease in 2006. I became involved with various groups, initially to learn more about the illness, then subsequently to try to make a difference. I wanted to illustrate the value of people with dementia still being involved in society, as it was sad to see people excluded and isolated because of an illness.

Stigma is a terrible thing whether real or perceived. Sometimes people with dementia think they are being stigmatised and this can be denied by other people but if someone was to search their conscience they would probably find in some instances that indeed they did stigmatise, because they were not wholly accepting of a person after diagnosis.

Labels can become so frustrating, as instead of being Jim, John, Lucy or Ann, you suddenly morph into a person with dementia first, followed by your name and other qualities. It's as if the rest of a person has vanished into thin air, never to return. In my experience, it is at the point of diagnosis or shortly afterwards that stigma begins to appear. It is as if friends and relatives can accept and be amused by someone's foibles prior to this and can warmly comment that they are getting eccentric as they get older. However, once dementia is diagnosed, it is as if a line has been crossed and some people don't want to be associated with someone with an illness affecting the brain. I have noticed that some people whizz straight to the end of the illness, as if their friend or relative was about to arrive there with no pathway in between. I don't know why this happens but ignorance of how the illness progresses may play a part, so education is the key.

My friend Dorothy experienced stigma after her mother was diagnosed with Alzheimer's disease. Prior to diagnosis, her mother had been doing a lot of odd things, such as serving tinned fruit with a main meal. Dorothy's sisters were all married with families but Dorothy was single and stayed with her mother. After diagnosis, the sisters all contributed in some way to her mother's care, which was very helpful. Dorothy worked full time and her mother went to a day centre each day within a hospital and she has nothing but praise for the care received there. However, all her mother's friends stopped coming to the house. The house used to be the hub where all they all met for coffee and a chat but it just ended. No explanation was given or asked for; it was like a clock had stopped never to be wound again. Dorothy probably felt it more than her mother, especially as time passed. Without dialogue between people at the time, it is not possible to know now if the friends' reaction was to the diagnosis, or how the illness manifested itself in Dorothy's mother and now it had a name. As the friends were still happy to visit prior to the diagnosis, it does appear that the diagnosis of Alzheimer's disease triggered the stopped visits. It could be that people now had a reason - as they saw it - to stop coming. Dorothy felt the people could have kept coming, staying only for a shorter time if need be.

More recently, another dear friend of mine related the story of how her father was treated by friends. Her father Charles was diagnosed with a mixed dementia last year. He used to have his own bakery business but retired some years ago. He was very keen on golf and walking and this was how he mainly filled his spare time. Charles was having problems at home misplacing things and he got so that he did not want to go to golf as it was too difficult. He said it made his head too busy, having to talk to his fellow golfers on a round and concentrate on the game. He also complained that even before he left the house he became exhausted getting ready and by the time he got to the car, he could not be bothered driving to the course. In a short time he stopped golfing and driving and this was before diagnosis. However, his wife Mabel was a great card player

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*Lynda Hogg is a Council member of Alzheimer Scotland and a Board member of Alzheimer's Disease International. Lynda was diagnosed with Alzheimer's disease in 2006. She previously worked at Heriot-Watt University, Pharmacy Research Unit, studying doctors' prescribing habits and after that moved to the Scottish Pharmaceutical General Council in a complex administrative role which involved working with pharmacists to provide a wide range of information and responses to queries.*

and they used to play every Wednesday afternoon at the house of a friend and his wife, Alexander and Margaret. They had all been friends for years, were all now retired and this became a ritual. They always enjoyed their time there and found the friendship very relaxing. Charles still managed to play cards with a little help from his wife. Charles and Mabel shared the diagnosis with their friends and continued to visit their home each Wednesday for card games. About a month later, Margaret started going out on the Wednesday and was not there in the afternoon. Alexander made a lame excuse for Margaret each week, such as shopping, dental appointments, or a chiroprapist visit. Charles and Mabel thought this strange, as this had never happened before in their long friendship. Although Charles had been diagnosed with a mixed dementia, he was still the same person as before - a very alert and capable gentleman. He noticed as the weeks went on that Alexander would get a telephone call when they were there, always about the time they were due to leave and Alexander always said it was a wrong number. Charles eventually queried this and Alexander, although flustered, told him the truth. Now that Margaret knew what was wrong, she did not want to keep up the friendship. Although she felt sympathetic, Charles asking the same questions had started to get her down. He usually missed the toilet when he used it and there was a wet floor to clean. Margaret knew she was being a coward but she just could not face the afternoons anymore. She felt that Charles would be better off at a day centre with people with dementia. Yet, the repetitiveness and missing the toilet had been happening before diagnosis and had been tolerated, so instead of knowing what was wrong being a bridge to acceptance, it was a pathway to stigma. The friendship ended.

Although in some respects Alzheimer's disease and other dementias are known about, due to a great deal of awareness raising, stigma can still exist. In both my illustrations there would have needed to be a lot more communication between everyone involved. Even if there had been, I'm not too sure if the friendships could have been salvaged. Perhaps with Dorothy's mother but with Charles, Mabel, Alexander and Margaret, I think the friendship was broken when Margaret decided to remove herself from the situation each week. I think it would have been far better to have a discussion between all four people and for them to be open about their feelings. Surely something could have been worked out. Alexander and Margaret could have visited Charles and Mabel and left when they thought it was appropriate. Also Charles would be using his own toilet, so Margaret would not have the problem she did not appreciate in her own house.

It is so unfortunate that being diagnosed with an illness can cause such problems. Personally, I am all for openness but I can understand why some people choose to keep the diagnosis to themselves or a few close family members. Encouraging more people to be open in theory should reduce stigma and I know of many instances where it has. People need to be accepted for who they are. It always astounds me that it can be friends who turn away, as if they are somehow tainted by association. People with dementia are normal people; they just happen to have an illness.

I would like stigma to disappear from all our lives ■



# On stigma

*Andrew Watt*

There are few things more frightening than the thought of losing your mind. Losing those last shreds of awareness that tether you to your life and the people around you. If you're lucky this notion will remain just that, a fear. An abstract thought that acts to occasionally cajole you into exercising more or eating better. But for others, a diagnosis of Alzheimer's disease or dementia can turn this fear into a reality, taking a healthy mind and slowly stealing it away as they watch it happen<sup>1</sup>. There are currently an estimated 36 million people living with dementia worldwide<sup>2</sup>. Thirty-six million people quietly slipping away from both themselves and the loved ones who surround them. In many cases these individuals are struggling with more than just their condition alone, they are struggling with the profound stigma that remains affixed to a diagnosis of dementia.

The stigma associated with dementia adds an additional burden to the already heavy load carried by all those who are affected. Emanating either externally, from the wider population, or internally, from the affected individuals and carers themselves<sup>1</sup>, such stigma acts to reduce people affected by dementia 'from a whole and usual person to a tainted and discounted one'<sup>3</sup>.

Until recently my father, Alan, was one of the many individuals living with dementia. He was diagnosed with younger-onset Alzheimer's disease at the age of 54, although we would later discover that this diagnosis was complicated by also having Lewy Body Dementia. The diagnosis changed his life irrevocably, and over the course of nine years he went from being a prominent surgeon to a frail old man as the diseases took their course.

As with most dementias, the deterioration in his cognition did not occur overnight. However despite this, small changes in his social circles began to evolve soon after his diagnosis. Whilst a solid few remained, many of his friends, including those from the medical community, stopped calling. Some made excuses but most simply faded away. Before long a similar pattern of desertion could be seen in my mother's circle of friends as well as my own and those of my siblings, leaving us all with a feeling of isolation as the social supports we had so carefully constructed slowly eroded away. This sort of social stigmatisation and isolation are commonly reported by people affected by dementia, with many relationships waning despite cognitive faculties remaining largely intact. It remains hard to know whether the shift in friendships arose from my own issues in dealing with the diagnosis or whether my friends had lacked the knowledge of how to cope during this hard time. In reality it was probably a little of both. Fear, anger, shame, guilt and a general awkwardness tend to hang heavily over the heads of both those diagnosed with dementia and their carers in the early stages of the disease, as attempts are made to reconcile the diagnosis with their everyday lives.

'People become very clever at being able to avoid you. It becomes a very lonely experience for many years.'

CARER

'Once diagnosed, friends soon disappear; they find it hard to see the decline in your loved one, and then once they have died, the carer has to start and make a new life and sometimes [new] friends'

CARER<sup>4</sup>

In many ways, the early stages of dementia are the forgotten years. With only minor adjustments, diagnosed individuals are often able to retain a sense of normality in their daily lives. In his initial years with the disease, my father was able to continue enjoying the travel, films and friends in much the same way as he had prior to his diagnosis, albeit with a slight increase in help from those around him. He even acted as a member of the Consumer Advisory Committee

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for Alzheimer's Australia (Western Australia) for over a year, passing on his insights on life after a dementia diagnosis. Despite this, I am ashamed to admit that a great deal of the stigma levelled at my father during this time emanated from me. In the early stages, it was easier to talk through him or not talk to him at all; to adjust to the loss that was to come rather than watching the disease slowly take its course. The heady mix of anger, guilt, shame and sorrow that his diagnosis had instilled in me resulted in my losing sight of who he was as a person, seeing instead the disease that would eventually claim his life. I lost a year to those wasted emotions. A year in which my father's mind remained clear but in which my fear and shame kept him at arm's length. In the end though it just took time; to adjust to the diagnosis and to realise that the time we could still share was more important than my own concerns.

As carers we are not immune to the stigma that continues to surround dementia and at times find ourselves perpetuating these notions rather than acting to halt them, particularly within those early stages. However, as time passes and our awareness grows, we are better able to see those affected by dementia as the individuals they are rather than the condition that afflicts them. Equally, it is imperative that we strive to challenge the stigma of dementia which pervades the wider community by ensuring that accurate representations of the condition are presented and an open discourse is established. Perhaps then the burden of dementia can in some small way begin to be reduced ■

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# Enhancing legal rights for people with Alzheimer's disease by improving quality

*Kees Blankman*

One of the effects of Alzheimer's disease is the growing loss of capacity. People with Alzheimer's disease find it more and more difficult to take care of their own legal and financial interests. This requires a legal framework that upholds a delicate balance between supporting people with Alzheimer's disease and respecting their decisions on the one hand and creating forms of representation and proxy-decision making for them on the other hand. International conventions, recommendations from the Council of Europe and domestic legislation as such cannot realise a tailor made solution for every situation. But they can facilitate the process of reaching this solution, introduce safeguards and remove barriers. As the international convention on the rights of persons with disabilities formulates in the fourth paragraph of article 12: '... measures relating to the exercise of legal capacity ... are proportional and tailored to the person's circumstances ...'

For legal experts and lawyers involved in contributing to this legal framework, the main concern must be to respect the rights and preferences of people with Alzheimer's disease. Introducing and applying additional provisions of representations such as guardianship measures is part of the delicate balance but should never have priority over our main concern.

I was fortunate to be chairperson of a group of experts for the Council of Europe that produced the text of the Recommendation on Continuing powers of attorney and advance directives that was adopted in December 2009. An advance directive is a written instruction that specifies what actions you want to be taken regarding your healthcare if you are no longer able to make those decisions. The second paragraph of principle 1 of this Recommendation is of paramount interest and reads: 'in accordance with the principles of self-determination and subsidiarity, states should consider giving those methods [continuing powers of attorney and advance directives] priority over measures of protection.' I fully agree with this principle stating explicitly that guardianship measures are the second best answer for situations of incapacity, and preference should be given to self-appointed representatives and arrangements. A recommendation differs from a convention; it does not compel but urges states to modernise their guardianship legislation and to introduce a system of continuing powers of attorney. A number of European states have already introduced such a system including a digital model for a continuing power of attorney, a national register and safeguards to avoid misuse. The names differ, but the mechanisms are generally the same whether it is called lasting powers of attorney (England and Wales), *Vorsorgevollmacht* (Austria and Germany) or *Mandat de protection future* (France). Other countries remain behind in providing an easily accessible legal provision for people with (an early diagnosis of) Alzheimer's disease to make arrangements for a future period of incapacity.

There is a lot of work to do for lawyers active in this field. The Dutch parliament, for example, is discussing a bill on guardianship reform that introduces more instruments of supervision by the courts and quality requirements for court appointed representatives with three or more appointments as a guardian. The proposals deserve support, but the government unfortunately failed to introduce a system of continuing powers of attorney. Two years ago, legal professionals started an initiative and came up with a model for a living will and a register. This model, however, is rather extensive and particularly suitable for more wealthy people. For financial reasons, this provision is not easily

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available for the greater public. It is, for example, twice as expensive as granting a power of attorney and getting it registered in Scotland. Scotland seems pretty successful in respecting the autonomy of incapable adults since the number of powers of attorney exceeds the number of guardianship measures.

Enhancing the rights of people with Alzheimer's disease does not stop when a convention or new national legislation has entered into force. I discern several challenges for the future. Some of them coincide with my personal ambition both as a researcher, a judge and an advisor of the Alzheimer Center in Amsterdam. One of the findings of a recent major research project on incapacity in care situations in the Netherlands is that the assessment of incapacity both in legislation and in practice is still underdeveloped. Improvement is necessary and I expect to be involved in drawing up proposals for improvement. Another finding of this study was the lack of a central point of information for guardians especially for guardians from the family. The level of quality in some cases turned out to be low. Courts appoint and fire guardians and sometimes provide the appointed guardian with brief information, but for non-professional guardians this is simply not enough. Because of the scope of their powers and the human rights of the people they represent, a more extensive infrastructure is needed for guardians in which guidance, education, information and perhaps supervision is available. Improving the infrastructure to my opinion cannot effectively be achieved by enlarging budgets. Raising public awareness and affinity are just as important. A side effect of creating a stronger infrastructure might be tackling the stigma that is still connected with Alzheimer's disease.

Rights of people with Alzheimer's disease are also at stake where it concerns the implementation of guardianship measures. Consider the architects of the Yokohama declaration. The declaration was accepted as the result of a World Congress on Adult Guardianship (Yokohama, September 2010) and contains a number of important principles regarding the attitude, knowledge and skills of adult guardians. Whether this document will grow into an international standard of professional guardianship is uncertain, but the first step has been taken.

The overarching theme seems to be enhancing the rights of people with Alzheimer's disease by improving quality, not just in legislation, but also in assessing incapacity, in standards for guardians, and in offering easily accessible information and support to guardians. Enhancing the rights of people with Alzheimer's disease will not result in eradicating the disease but it will certainly improve the quality of life of a growing number of people in our world ■

# Examples of programmes to reduce stigma

There are many misconceptions that build and maintain stigma associated with dementia, such as the myth that memory loss is a normal part of ageing or that a person with dementia can no longer be an active member of society. These myths must be dispelled, and an important way to achieve that is education.

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 such as research centres on a national, regional and local level. 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.

This chapter highlights some of the efforts that have been made around the world to raise awareness and reduce stigma. We have divided them into six categories:

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

## People with dementia speaking out



**It could be argued that the most powerful means of reducing the stigma and correcting the common misconceptions surrounding dementia is for those who have the disease to be seen and heard more than they are now. Increasingly, people with dementia are coming forward to show that an active life after diagnosis is possible. Networks are forming around the world, bringing together those living with dementia for mutual support and to strengthen the call for change.**

### **The Dementia Advocacy and Support Network International**

The Dementia Advocacy and Support Network (DASN) International was formed in 2000 through an online social forum. The network of people with dementia from around the world aims to: 'Promote respect and dignity for persons with dementia, provide a forum for the exchange of information, encourage support mechanisms such as local groups, counselling groups and Internet linkages, advocate for services for people with dementia, and assist people to connect with their local Alzheimer's association.' A key focus of the network is empowering people with dementia to becoming actively involved in their own care and treatment and to improve the lives of others by speaking out.

In July 2001, DASN International put forward a proposal to Alzheimer's Disease International (ADI) for greater inclusion and recognition of the needs of people with dementia. DASN International's Christine Bryden became the first person with dementia to speak about her diagnosis at an international conference. This landmark presentation took place at the ADI conference in New Zealand in October 2001 and the inclusion of people with dementia has since become an essential feature of the ADI conference programme. In 2003, Christine became the first person with dementia to be elected to the ADI Board of Directors.

More than ten years later, DASN International continues to exist as an online network, bringing together some of the most powerful voices from the field in an effort to ensure that people with dementia are heard.

## Scottish Dementia Working Group



The Scottish Dementia Working Group was formed in 2002 as a national campaigning group run by and for people with dementia. Their three key aims are to highlight the importance of early diagnosis, to improve nationwide access to post-diagnostic support, and to ensure a well-trained workforce in the dementia field.

The Group has gained a strong reputation for providing inspirational speakers at events and conferences across the world, providing the best evidence that people with dementia can lead an active life after diagnosis. The Group gives frequent interviews, runs training sessions for professionals in the field, and has produced three DVDs, a guide for those who are newly diagnosed and a joke book.

In 2010, the Scottish Dementia Working Group was involved in the development of Scotland's Dementia Strategy. They are now a partner in overseeing the implementation of the Strategy, with quarterly meetings taking place with the government to discuss progress.

The Group is funded by Alzheimer Scotland, which also provides support and training. There are currently more than 140 members making up the Scottish Dementia Working Group. Similar groups exist in the Netherlands (Kerngroep Dementia), Belgium (the Fighters), England and the Czech Republic.

## Alzheimer's Association National Early-Stage Advisory Group

USA

The Alzheimer's Association National Early-Stage Advisory Group, now in its seventh year, is comprised of men and women from across the U.S. who provide their unique insight on the needs of people living with Alzheimer's and their caregivers. Their work includes raising awareness of issues related to dementia, advocating for increased funding for research and support services, and helping the Association provide the most appropriate programs and services for people living with early-stage Alzheimer's and other dementias.

The Early-Stage Advisors meet once a month, serve a one-year term and, during this time, serve as national

spokespeople at educational events and in the news media.

The Advisors have played a key role in some of the Association's successful advocacy efforts, including helping to secure the addition of younger-onset Alzheimer's to the USA's Social Security Administration's Compassionate Allowance Initiative and the creation of the first US national Alzheimer's plan. They also created the Principles of a Dignified Diagnosis, the first statement of its kind written to improve physician and clinician interactions with people with dementia. In August 2012, current and former Advisors developed tips on how to combat stigma based on their personal experiences, which will be published during World Alzheimer's Month.

## European Working Group for People with Dementia

In April 2012, the Scottish Dementia Working Group collaborated with Alzheimer Europe and Alzheimer Scotland to bring together people with dementia from across the region to discuss the formation of a European Working Group for People with Dementia<sup>1</sup>. The formation of this group was prompted by Alzheimer Europe who will allocate a position on their Board for a person nominated by the group. The Working Group will also act in an advisory capacity for Alzheimer Europe.

The initial meeting, which took place in Glasgow, Scotland, was attended by nine people with dementia from the Czech Republic, England, Germany, Ireland, the Netherlands and Scotland.

## Breaking barriers in Japan

To address the stigma associated with dementia, for the first time Japanese people with dementia publicly shared their experiences at the 20th International Conference of ADI in 2004. Sixteen people with dementia attended the event, which included a press conference run by a person with dementia that generated widespread news coverage across the country<sup>2</sup>.

This conference marked a real turning point for people with dementia in Japan and paved the way for further events providing an opportunity for people with dementia to speak out, including the country's first People with Dementia Conference, which took place in October 2006. At the conference, people with dementia drew up an appeal outlining how they wished to be treated by various groups within society<sup>3</sup>.

## I CAN! I WILL!

The I CAN! I WILL! library was launched in September 2011 as a place for people with dementia, carers and others within the dementia field to share their ideas for raising awareness and reducing stigma. The website breaks ideas down into 'books' for different audiences

including medical professionals, people with dementia and Alzheimer associations. In addition to adding their own stories or ideas, visitors to the site can comment on and rate other stories.

Between 21 September 2011 and 20 May 2012, almost 5,000 unique visitors viewed the site. More than 120 ideas had been posted on the site by May 2012 and an email subscription tool is available for those who wish to be informed of new posts.

The I CAN! I WILL! ideas library was developed by Richard Taylor from the USA who is living with dementia, in collaboration with Laura Bramly and ADI.

### **The EDUCATE programme**

#### **England**

The Early Dementia Users' Co-operative Aiming to Educate (EDUCATE) project was developed as a community outreach programme for those in the early stages of dementia in a community in Manchester, UK. The project aims to improve the confidence of those who have recently received a diagnosis by providing them with opportunities for communication about their experience with a variety of groups including school children and social care professionals. An 18-month pilot project began in 2009 and by April 2012, 20 volunteers were involved with the project. Group meetings take place on a monthly basis where it is decided who will be presenting to which group. The project is currently funded by the European Union through their Senior European Network Support programme<sup>4</sup>.

### **'It's not a disgrace...it's dementia'**

In March and June 2012, Alzheimer's Australia NSW launched three short films aimed at Assyrian, Cambodian and Croatian communities, providing information and personal perspectives from carers in the native language in an attempt to dispel the myths and break down the stigma associated with dementia. The 'It's not a disgrace...it's dementia' short films promote dementia as an illness and not a normal part of the ageing process. Award-winning films in Arabic, Ukrainian and Serbian under the same title were released in 2010. The series was produced with the support of Australia's Department of Health and Ageing and Ageing Disability and Home Care.

## **Dementia-friendly communities**

**A new trend is emerging following identification of the essential function of communities to safeguard the inclusion of people with dementia and their carers as active and respected members.**

### **Dementia Friendly Communities**

#### **Ireland**

In 2011, the UK's Department of Health commissioned community interest company Innovations in Dementia to seek the views of people with dementia and carers about the development of Dementia Friendly Communities (DFC). They highlighted five aspects that were considered most important in forming such a community: physical environment, local facilities, support services, social networks and local groups.

Based on the outcomes of this project, the Alzheimer Society of Ireland hosted internal workshops to review their activities and discuss improvements that could be made in-line with the DFC findings. These discussions culminated in a report, released in March 2012, outlining the Society's four key aims: to develop local support groups and one-to-one support; the on-going incorporation of the DFC findings into the Society's work; the development of guidelines on how to create a DFC for wider use; and initiation of new services that will assist in connecting or re-connecting people with dementia with their community<sup>5</sup>.

Implementation of new programmes across Ireland's counties has already begun and includes intergenerational activities and one-to-one support.

### **Strategy For Excellence In Dementia Care**

#### **San Francisco, USA**

A panel of dementia experts, commissioned by San Francisco's Department of Aging and Adult Services, called for an urgent response to the growing numbers of people with dementia living in the state in December 2009. The panel's report, 2020 Foresight: San Francisco's Strategy For Excellence In Dementia Care, highlighted 14 objectives and 35 recommendations to address the problem, including the development of policies and practices to ensure the needs of those with memory loss were met within communities. It was hoped that this particular objective would inform, and be informed by, endeavours to create dementia friendly communities elsewhere on a national and international level<sup>6</sup>.

The project is on-going and focus for implementing the plan is on education and training, improvements in housing systems and access, and encouraging the involvement of people with dementia in their community. Training has been provided for professionals including the police, bus drivers and airport security staff. Discussions are underway between a number of service providers as to how cost-effective, appropriate housing

services can be improved or developed for those on a lower income.

An event, due to take place in November 2012, will include discussion and review of the work being carried out for the plan in line with changes to the government's care policies and practices. Those involved in the implementation of the plan, including the Alzheimer's Association of Northern California and Northern Nevada and a new workgroup created for the project, are now directing their attention towards making the areas in the community where people with dementia connect with others 'dementia capable', an essential feature of a dementia friendly community.

### **The Dementia Challenge**

#### **England**

As part of the UK Prime Minister's Dementia Challenge, launched in March 2012, a Dementia Friendly Communities Champion Group was formed to fulfil one of the four key objectives of the Challenge: to have up to 20 towns, cities and villages taking part in a programme to become more dementia friendly by 2015. The Champion Group – which includes industry leaders, town and city representatives, people with dementia and carers – will work towards the development of a nationwide campaign to raise awareness. As an initial step towards defining a dementia friendly community and addressing the common issues currently faced by people with dementia and their carers in the UK, members of the public were given the opportunity to share their thoughts and experiences. The findings from this outreach activity

### **La Memoria es el Camino**

Spanish journalist, Guillermo Nagore, is currently walking 7,050km across 15 countries as part of an awareness-raising effort created by Confederación Española de Asociaciones de Familiares de Personas con Alzheimer y otras demencias (CEAFA). The project, La Memoria es el Camino (The Memory is the Way), began in Spain on 18 March 2012 and is expected to continue until December when Guillermo reaches Jerusalem.

The trip will incorporate Italy, Croatia, Syria and Lebanon among other countries and as he progresses Guillermo will collect stories from people with dementia and family carers to share through social media networks.

This activity is organised by CEAFA to raise awareness of the growing impact of dementia and encourage the Spanish government to develop and implement a national dementia plan to address this.

will contribute to a report prepared for the Prime Minister in September 2012.

### **Ville Amie Démence**

#### **Belgium**

Twenty-five cities, municipalities and provinces in Belgium are already operating as a 'Dementia Friendly City' (Ville Amie Démence) as part of a national network to improve the lives of people with dementia and their carers. The Dementia Friendly Cities Charter, drafted in March 2011, focusses on sensitisation within communities, the rights of people with dementia, the development of appropriate services and action within cities and consultation. Cities that have signed the Charter host and develop a range of activities to ensure that people with dementia and their carers remain connected to their community.

La Ligue Alzheimer, the national Alzheimer association in Belgium, offers training sessions and documentation to assist those cities who sign the Charter with implementing their plans. Activities developed for people with dementia and their carers, which are all free of charge, include Alzheimer Cafés, home assistance and intergenerational programmes. 'The Fighters', a group for people with dementia to share their experiences, is also an important part of this programme.

### **War on Dementia**

#### **South Korea**

As part of their mission to address the rapidly ageing population and growing numbers of people with dementia, the government of the Republic of Korea introduced their 'War on Dementia' in September 2010. As part of this campaign, the national Alzheimer association coordinated training programmes in an effort to raise awareness and reduce stigma. A range of measures have been taken, including the training of large numbers of people as 'dementia supporters'. The programmes were attended by a variety of groups, from young school children to those working in public places who are likely to come into contact with people with dementia. Nursery school children also spend time playing with residents of nursing homes and a number of schools offer community service credit to those who work with people with dementia. Funding for the new activities and improved services for people with dementia was generated by a 4% increase in the national health insurance payments of all of those living in the Republic of Korea. The association trained 5,000 individuals as well as a number of other institutions before the responsibility for implementing the programme was returned to the government<sup>7</sup>.

## Dementia and Age-Friendly Neighbourhoods

### Australia

Alzheimer's Australia NSW (New South Wales) developed a discussion paper, launched in July 2011, under the heading Building Dementia and Age-Friendly Neighbourhoods. The paper, one of a series on dementia-related topics, includes a dementia and age-friendly outdoor design checklist with practical suggestions for improving the physical environment such as pedestrian-only walkways, good lighting and the use of a dementia symbol in hospitals<sup>8</sup>. The paper was the result of a series of consultations with consumer committees made up of 60 people with dementia and carers.

The paper calls on governments in New South Wales to incorporate the information within the paper into local and regional policy documents and planning resources.

## Alzheimer and You

### Germany

Deutsche Alzheimer Gesellschaft, the national Alzheimer association in Germany, host a website under the title Alzheimer and You, aimed at children and young people. The purpose of the site is to encourage increased contact between children and people with dementia as well as to provide dementia-related information that can be used in schools and support collaboration between schools and care homes.

The website contains a variety of information, including advice on how to deal with dementia if a relative is diagnosed, signposting to counselling services and volunteering opportunities. A forum is also available for children and young people to find the information or support they may need.

In 2007, as part of the website launch, Deutsche Alzheimer Gesellschaft ran a contest, Alzheimer & You – Show your commitment, inviting 14-21 year-olds to submit a creative piece based on their experiences and encounters with people with dementia. More than 100 entries were received in a range of formats, including photography, film and paintings.

As part of their on-going efforts towards making Germany more dementia friendly, Deutsche Alzheimer Gesellschaft also developed an information pack about dementia for emergency service workers as well as those who work in supermarkets and banks. The pack, which gives examples of the daily life of a person with dementia, continues to be used by the association's regional branches for training purposes.

## Age-Friendly Cities and Communities

### World Health Organization

In June 2010, the World Health Organization (WHO) officially launched the WHO Global Network of Age-Friendly Cities and Communities. The purpose of the Network was to coordinate the exchange of knowledge

and information between cities to enable them to become more inclusive of and accessible for older residents.

In preparation for the development of the Network, the WHO commissioned research in 33 cities across 22 countries in 2006 to ascertain the opinions of their older residents on eight key areas including respect and social inclusion, social participation, outdoor spaces and buildings, appropriate housing, community support and health services. Although the programme is not targeting dementia specifically, the stigma of old age is connected with the stigma of dementia. We hope that the consideration, inclusion and respect will extend to older people with dementia.

As part of the initiative, those cities signed up to the Network must produce a plan based on two years of planning, three years of implementation and a progress evaluation before improvements continue to be made.

## Alzheimer Café



Alzheimer Café Belgium

The first Alzheimer Café® opened its doors in 1997 in the Netherlands. In his contacts with people with dementia and their families, Dr Bère Miesen had noticed that talking about the illness, even between partners or within a family was often taboo. Knowing that making dementia discussable, and providing information about it and its consequences, is very important for the acceptance of the illness, Miesen thought that it would be good if all those involved could meet each other in a 'relaxed forum' to exchange experiences and to talk about dementia. And what better way to describe such a 'relaxed atmosphere' than with the word 'café'? Alzheimer Nederland adopted the idea and enabled their branches to set up Alzheimer Cafés including producing a manual and a training programme for discussion leaders. There are now around 200 Alzheimer Cafés in the Netherlands, and other countries have successfully adopted the model.

# Dementia experiences

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

## Memory Footprints

Canada

The Alzheimer Society of Montreal in Canada introduced their interactive workshop, Memory Footprints, in 2004. The programme aims to give healthcare workers an insight into what it feels like to have Alzheimer's disease that, in the long term, will support them in considering alternate interventions and increase their holistic understanding of the person they care for<sup>9</sup>.

A major focus of the project is on the creation of empathy. Practical activities encourage participants to identify their personal stereotypes associated with Alzheimer's disease and recognise the consequences of these perceptions from the point of view of the person with dementia. The workshop also encourages the development of skills for providing person-centred care. Participants are asked to share their personal strengths, weaknesses and experiences as a professional carer of people with dementia and set individual goals for the following months.

The workshop is conducted in either English or French. Those trained include volunteers and healthcare workers at community organisations, non-profit associations, long-term care facilities, adult day centres, hospitals and training conferences. So far, more than 500 individuals have been trained through the project across three Canadian provinces and it now forms part of the Society's Core Training Program for Health Care Professionals.

## Alzheimer Experience

Netherlands

In May 2011, Dutch film company Submarine, supported by Alzheimer Nederland, launched Alzheimer Experience to address the misunderstanding, frustration and difficulty in communication experienced between a person with dementia and a carer. The educational programme aimed to close the gap between the person with dementia and carer's perceptions of the world by offering free, interactive, web-based films following the lives of two people with dementia through all stages of the disease. The 22 scenes that make up the two hours of film include a choice of perspectives generated from evidence-based experiences and scene-specific information about dementia.

By March 2012, the Alzheimer Experience website had received 166,621 visits with an average of 7.59 minutes spent on the site. Ninety-four percent of visitors to the site were informal and professional carers. Discussion is now underway about disseminating the programme internationally.

## Sort Me Out

Singapore

Recognising the potential reach of targeting the general public through social media, Alzheimer's Disease Association (ADA) Singapore and advertising agency Grey Singapore developed and launched Sort Me Out, an innovative application for social networking service Facebook, in December 2011. The viral campaign aimed to re-create the experience of memory loss in Facebook-users by encouraging them to install the application which would then connect with their account and simulate the gradual erasing of their content, including friends, pictures and videos. The application reached a total of 77 countries as well as bringing more visitors to ADA's website.

## Alzheimer Experience

Ecuador

The Alzheimer Experience campaign took place in a number of supermarkets in Ecuador on World Alzheimer's Day 2011. On the morning of 21 September, supermarket staff re-arranged the stores' stock, resulting in shoppers not being able to find what they were looking for before being informed at the cash register that they were part of an activity that aimed to provoke the feelings people with dementia may experience in a supermarket<sup>10</sup>. They were also invited to give a donation to the cause. This activity, coordinated by Fundación Alzheimer Ecuador, reached thousands of individuals and all funds raised on the day were channelled back into the work of the Fundación.

## UK 'Living Well' campaign

The UK campaign 'I have dementia, I also have a life' demonstrated a targeted approach to dispelling fears. Targeting a 40 to 60-year-old predominantly female audience, the campaign – which used television, radio, online and print media – featured people with dementia. The advertising, which aimed to raise levels of understanding, was developed as a result of qualitative research. The research, which was conducted with people who had little or no experience of dementia, showed what was behind the stigma. It showed great fear of dementia – fear of getting the condition and fear of engaging with people with dementia. The advertising campaign therefore sought to 'normalise' dementia rather than to 'medicalise' it, since the latter could lead to increased fear.

## 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.**

### **InfoMobil** Switzerland



Association Alzheimer Suisse, the national Alzheimer association in Switzerland, conducted a pilot campaign, InfoMobil, in Bern in March 2009. The InfoMobil is a converted caravan containing information handouts, flyers and brochures on a range of dementia-related topics. The project aimed to increase public awareness and break the taboo surrounding dementia.

In May 2010, the campaign was taken further, visiting 12 locations in 26 days following arrangements with supermarkets, hospitals and local communities. The InfoMobil was manned by volunteers recruited from nursing homes, outpatient care, organisations for the elderly, the Red Cross and respite services. As a result of the campaign, which continued throughout 2011 and into 2012, the association has seen an increase in donations, volunteer recruitment, and demand for cantonal services and requests for presentations to be given to healthcare or charitable organisations.

### **Memory Bus** Scotland

Alzheimer Scotland's first Memory Bus was unveiled in February 2011. The purpose of the bus is to provide information and advice to people with dementia and their carers as well as raising awareness among communities both in remote, rural communities and towns and cities<sup>11</sup>. The bus travelled extensively throughout Scotland between May and September 2011, stopping at shopping centres, car parks, village halls, farmers' markets and high streets to disseminate information.

### **Dementia Community Roadshow** UK

In partnership with retailer Tesco, Alzheimer's Society (England, Wales and Northern Ireland) and Alzheimer Scotland launched the Dementia Community Roadshow in June 2011. The Roadshow, which aims to reach 100,000 people over a three-year period with three vehicles, stops at Tesco supermarket car parks around the country with voluntary staff from Alzheimer's Society and Alzheimer Scotland providing information, advice and signposting to local services. Members of the public can also request the Roadshow at their nearest Tesco car park via an online form on the campaign's website.

### **Memory Van** Australia

Alzheimer's Australia WA (Western Australia) and NSW (New South Wales) both provide a Memory Van service, offering members of the public the opportunity to take part in a Brain Fitness computer training programme as well as providing useful information and literature about dementia. Both vans can be booked for events and free memory tests are also available in the WA van. The Alzheimer's Australia WA Memory Van receives more than AU\$1.5 million under their programme for state-specific activities, including the operation of the Memory Van and the Dementia and Memory Community Centre.

### **Muistibussi** Finland



The national Alzheimer association for Finland, Muistiliitto ry, organised a Muistibussi (Memory Bus) to tour the north of the country around World Alzheimer's Day in September 2009 and in 2011. The purpose of the project was to provide information to those living in rural communities with the bus stopping at various public car parks across the region. Staff were available on the bus to offer advice and information.

## Promoting earlier diagnosis

Chapter 1 highlights the role that stigma plays in preventing people with dementia and their carers from acknowledging symptoms they, or a friend or family member, may be experiencing. This delays the help-seeking stage that provides them with important treatment and support. Earlier diagnosis enables earlier understanding and better support for people with dementia and carers, helping to keep them included in society and enhancing their quality of life<sup>12</sup>. Having a diagnosis also gives people with dementia the opportunity to speak about their experiences and advocate for themselves.

Alzheimer associations in high income countries, where support services are more readily available, have conducted nationwide campaigns to combat stigma by promoting the benefits of earlier diagnosis.

### Brain Tour

The Alzheimer's Association (US) has an interactive Brain Tour on its website that provides a straightforward explanation of how the brain works and how Alzheimer's affects it, in 15 languages. It is one of the most popular pages on the Association's website. The Brain Tour is a 16-slide presentation that destroys the myth that Alzheimer's is normal ageing. The Brain Tour is also available on CD-ROM in English.

### Reducing stigma in Iran

A major step towards reducing stigma in Iran has been taken following successful awareness-raising activities and support groups run by Iran Alzheimer Association. The association's day care centre has become the focus of a number of television documentaries highlighting the activities and routines of people with dementia who attend. While, in the past, family carers have only granted authorisation for people with dementia to be filmed or photographed from behind or with their hands and faces blurred, families are now increasingly willing for their loved ones to be shown actively participating at the centre. Family carers are also more open to sharing their experiences as part of the documents, which are a useful tool in continuing to de-stigmatise dementia in Iran.

### Let's Face It

Canada

The Alzheimer Society of Canada conducted an online survey in 2011 to determine how long after experiencing the symptoms of dementia people waited before seeking medical advice. The survey was completed by 958 carers of whom almost half had waited a year before visiting their doctor and 16% had postponed seeking help for two years. Three quarters of those surveyed had wished that they had received an earlier diagnosis. The campaign, Let's Face It, encouraged greater recognition of the warning signs of dementia and sought to reduce the associated stigma in order for people with dementia to receive support and treatment sooner in the disease process.

### Know The 10 Signs: Early Detection Matters

USA

In 2008, the Alzheimer's Association introduced its 'Know the 10 Signs: Early Detection Matters' campaign, aiming to increase awareness of the 10 Warning Signs of Alzheimer's and promote the benefits of early detection and diagnosis. The campaign launched with a stream of news media coverage focussed on the message 'Know the 10 Signs' being broadcast over a period of two months.

An Alzheimer's Early Detection Alliance (AEDA) was formed and more than 1,400 companies have since joined the Alliance, ensuring their employees are better educated about the 10 Warning Signs.

The campaign was funded by a prize of \$1.5 million from the 2008 Members Project from American Express after receiving more than 24,000 votes from American Express card members<sup>13</sup>. The 10 Warning Signs continue to be used widely through the world and for various training programmes within the USA.

The Association works closely with people living with dementia who are willing to speak out about their experiences and the value of early detection.

### Worried about your memory?

UK

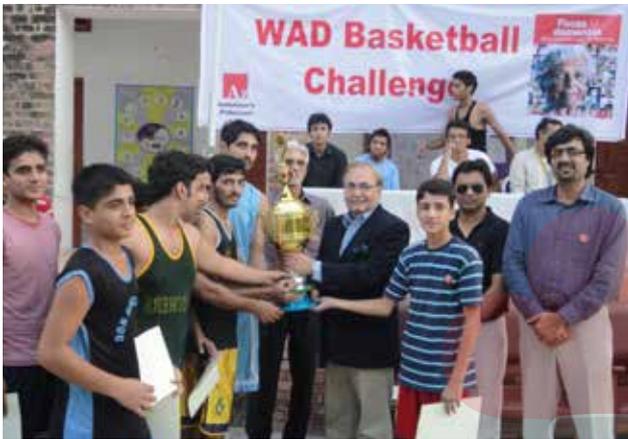
The Alzheimer's Society (UK) launched their Worried about your memory? campaign in May 2008 to raise awareness of the early signs of dementia and encourage those who were concerned to visit their doctor. A range of materials were made available for order with packs being sent to more than 9000 GP surgeries in England, Wales and Northern Ireland periodically over 12 months. Campaign packs included a CD-ROM to support doctors in the diagnosis process as well as leaflets, branded leaflet dispensers and posters for display. An additional booklet with further information was also made available to order with translated versions in ten languages and audiotape and Braille alternatives<sup>14</sup>.

## Art and physical activity and dementia

**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. Physical activity programmes for other community groups that aim to raise awareness of dementia have also proven to be very effective.**

### **World Alzheimer's Day Basketball Challenge and Interschool Sports Festival**

Pakistan



On World Alzheimer's Day, 21 September each year, a host of awareness-raising events take place across the world, including Memory Walks, educational seminars and information stands in public spaces. In 2011,

### **Memory Walk**

Memory Walk® was started by the Alzheimer's Association (US) in 1989, and in a few years became its primary fundraising event. Starting in 1999, ADI promoted the spread of Memory Walk around the world, with the support of the Alzheimer's Association. The first national Memory Walk in the UK was held in 2003 and many associations around the world now hold Walks annually for World Alzheimer's Day.

Memory Walk is an organised walk where participants walk a planned route and are sponsored to do so. As well as fundraising, the public walks help to generate awareness – often branded clothing, stickers and posters are used. In some countries, the walks have no direct fundraising element, but are successfully used to raise awareness both among the public that they come into contact with and additional in the news media.

Alzheimer's Pakistan organised two sporting events to raise awareness of dementia. The World Alzheimer's Day Basketball Challenge, organised in collaboration with the Lahore Basketball Association, saw young players from the Lahore District Basketball Team take on the Don Bosco Club Team. The activity was a great success and gained national media coverage for the cause.

An Interschool Sports Festival was held in September 2011, bringing together children from a number of schools to participate in activities while learning more about dementia and how communities can help to provide services and support for people with dementia and their families.

### **A Chorus for Older Adults**

USA

A Chorus for Older Adults with Alzheimer's disease and their family members was developed in New York, USA, to investigate the therapeutic qualities of music for people with dementia and their families. The project, led by Dr Mary Mittelman from the NYU Langone Medical Center, aimed to improve the quality of life of people with dementia and their carers by bringing them together with others to form a chorus.

The project began in June 2011 with 11 people with dementia and their accompanying family members who found out about the program through support groups, the New York City chapter of the Alzheimer's Association, the Meet Me at MoMA programme (see below), and the NYU Alzheimer's Disease Center. The chorus named themselves The Unforgettables and rehearsed for 13 weeks before their first concert at St. Peter's Church in Manhattan, New York. The concert was well-attended by the choir's family and friends as well as members of the community, and received local and national news media coverage both online and on television.

Although the pilot project has now concluded, the chorus continue to meet, rehearse and perform in concerts – they just had their fourth concert – and now contribute to the cost of the project. The activity has proven very effective in not only providing pleasure and improving the quality of life of the people with dementia and carers involved, but also assisting in educating the wider community about the potential of taking part in enjoyable activities with people with dementia.

### **Museum visits for people with dementia**

USA, Israel and France

The Museum of Modern Art (MoMA) in New York, USA, launched their Meet Me at MoMA museum tours programme in 2006. The tours, which include groups consisting of approximately 8 people with dementia and their carers, take place once a month on a Tuesday when the museum is closed to other visitors. Each tour lasts around 90 minutes, taking in and discussing four or five pieces of artwork, and is specifically for those in the early stages of dementia. Educators at the museum

receive training from local chapters of the Alzheimer's Association as well as internal training to continually improve the visitor experience.

The programme has shown clear evidence of a range of benefits for both the person with dementia and carer<sup>15</sup>, including improved social engagement with many participants expressing a desire to extend their visit to incorporate more social interaction with others. Participants reported the pleasure of being able to be in a place where they didn't have to worry about stigma. One person with dementia commented that at the museum, he felt like a person again.

Due to the success of the programme, MoMA's educators have conducted training workshops for staff in more than 50 museums across the USA. A guide for museums and care organisations wishing to host similar programmes has also been created.

In response to the introduction of the French National plan for Alzheimer and related diseases 2008-2012, the Mayor of Nice and the Centre of Memory Resources and Research organised a number of museum visits for people with dementia and their families as a form of art therapy through which their quality of life could be improved and they would feel more engaged in their society<sup>16</sup>. The project completed a very successful pilot including tours in five museums and, in 2011, 30 tours in 10 venues took place. Additional art-based activities have now been introduced, including percussion workshops and, most recently in June 2012, an innovative activity to

encourage the use of the senses in people with dementia through heritage in food, song and tradition<sup>17</sup>.

Inspired by the work in New York, the Alzheimer's Association of Israel now host their own museum tours. The tours currently take place in six museums in Israel and people with dementia and their families are welcome to join. The programme operates through day care centres and other services used by people with dementia.

### 800 kites fly over Monaco

On World Alzheimer's Day 2011, Monaco's Alzheimer association Monegasque Association for Research on Alzheimer's Disease (AMPA) coordinated the flying of 800 kites over a 70km expanse of the Côte d'Azur. In preparation for the event, and to encourage intergenerational activity, AMPA worked with schools to conduct paint workshops, allowing children and people with dementia to work together to design their kites. A key aim of the event was to reduce stigma by showcasing the ability of people with dementia to continue to live an active life after diagnosis<sup>18</sup>.

### Nationwide Caravan to train Ninchishō (Dementia) Supporters, Japan

In Japan, the word for dementia, Chihō, had been in use for a long period of time. However, the word has been accused of carrying contemptuous connotations, as Chi indicates stupidity and hō means idiocy. In 2004, the Japanese government changed the administrative term for the word dementia from Chihō to Ninchishō, meaning cognitive disorder.

After the change, the government launched a nationwide campaign, Ten years to understand dementia and to build community networks, to raise public awareness and understanding of dementia.

At the heart of this campaign is the Nationwide Caravan to train Ninchishō (Dementia) Supporters programme. This programme provides specialised seminars for the public held at schools and offices and for community groups across the country. The purpose of the seminar is to encourage individuals not to devote their whole life to caring for a person with dementia as this is believed to be unrealistic.

By the end of the seminar attendees are expected to have a good understanding of dementia, freeing themselves from any prejudice they may have, and to become supporters and advocates for those living with dementia in their everyday lives. Those who attend the seminars become Ninchishō (Dementia) Supporters.

Lecturers of the seminar must complete a six-hour training workshop to develop their knowledge enough to be able to deliver the seminar's content.

During the 90-minute Ninchishō Supporter seminar, attendees learn about the disease itself, how it affects the lives of those living with dementia and what they should know in order to effectively support people with dementia. Standard text and video materials are used nationwide for the seminars, with variations according to the attendee groups (for example, schoolchildren).

The seminar covers seven key areas including recognition of the symptoms of dementia, diagnosis and treatment, the role of each health care professional, prevention, attitudes towards people with dementia, and understanding of the caregiver experience. Over 3.3 million people in Japan had attended this seminar as of March 2012.

## SUMMARY

This chapter has presented some of the efforts to address the challenges that stigma presents. Other campaigns and activities exist in all parts of the world. These activities can have an impact on the community, regardless of their size. A small community event or ongoing support service can lead to heightened awareness of the issues.

It is essential that people with dementia themselves are not overlooked. Their interests and needs, along with those of family carers, belong at the heart of every campaign. We have seen how successful the growing networks of people with dementia are, and the difference that their willingness to speak about their experiences can make.

The creation of dementia-friendly communities presents a huge challenge for any country, but it is encouraging to note that governments are increasingly eager to work with national Alzheimer associations and other community groups towards the development and implementation of such schemes. The World Health Organization, with their Age Friendly Cities and Communities initiative, is ideally placed to call for more countries across the world to commit to this challenge. However, although the initiative addresses many issues and makes recommendations that are beneficial to older people in general, there is a need for further inclusion of people with dementia and their carers.

There is also a need for more awareness-raising programmes – and the resulting stigma-reduction – in lower income countries. This chapter has highlighted the great ability of national Alzheimer associations across the world to use the often limited resources they have available to them to implement a regional or national campaign to reduce stigma and raise awareness. However, there is a great need for more support from governments and collaboration with other non-governmental organisations, particularly in the developing world, to ensure these projects are developed with all available resources and ultimately reach their intended audience.

A number of these projects have shown that change is possible without the need for additional funding or services. Existing arrangements can be of great benefit to people with dementia and their carers if they are suitably promoted and well-maintained.

A great deal of easily-transferable information already exists in this area and the key now is not only further implementation, but the sharing and transfer of knowledge across regions and countries.

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## Stigma: a personal view

*Nori Graham*

In so many countries, to be old is shameful; to be mentally ill as well as old is doubly shameful. In so many countries, people with elderly relatives who are also mentally ill are ashamed and try to hide what they see as a disgrace on the family. That is what I mean by stigma. My career in the public and voluntary sectors has been dedicated to make a difference to older people with mental illness, especially dementia, and their carers so as to reduce and hopefully remove such stigma completely.

In the late 1970s I started my professional life as an old age psychiatrist. There were already a very few role models, such as my first consultant, Professor Tom Arie, who had demonstrated how much there was to do and how, with grit and determination, one could make a change. There was no competition for jobs as no one wanted to work with older people with depression and dementia. They were stigmatised. After all, it was accepted belief that there was nothing one could do to cure or even alleviate what was then seen as an inevitable accompaniment of the ageing process.

Around this time, excellent epidemiological research identified the prevalence of depression and dementia both in the community and institutions. These studies made the case for seeing them both as distinct illnesses experienced by only a small percentage of the elderly population. Clearly neither depression nor dementia were inevitable accompaniments of growing old. Further, it was possible to diagnose, treat and offer supportive care to all those affected. I was appointed to set up a new service for older people with mental illness. It was an exciting challenge to start up a service from scratch. I worked out what was needed and asked for a little at a time until I built up a comprehensive multi-disciplinary community orientated service for older people with the full range of mental illnesses. As with everything else described in this article, there were many others who contributed to the achievements that were obtained.

It took patience and close collaboration with everyone concerned, but in particular the patients, their families, the family practitioners, the other health professionals of all disciplines, academics and managers. They all needed convincing; the attitudes of many of them were fashioned by the stigma that then clouded work with the elderly mentally ill. The service grew slowly but eventually achieved an international reputation both for the quality of its clinical work and for its research programmes.

Our acute beds were in the teaching hospital alongside medicine, surgery and paediatrics. That really helped to remove the stigma. Our longer stay and respite beds for people with dementia were in a lovely small hospital surrounded by gardens in the middle of Hampstead Health – a well-known beauty spot. The service was opened by the Prince of Wales – a great antidote to stigma there. Families were proud to visit their relatives in such a setting. We assessed all new patients in their own homes at the request of the family practitioners and most people were treated and followed up at home and never needed to come into a hospital. We never had a waiting list. The moment a referral was made an arrangement to visit was made. This service was provided by the National Health Service with no private payments involved. It was available to everyone and even the most privileged members of the community took advantage of it; everyone was treated equally.

I am in no doubt that to reduce stigma it is vital that quality treatment and care take place in quality environments – places any of us or our families would be proud to be treated in ourselves. Quality services such as these need to be sensitive and specific to an area's needs. But given the motivation and the resources they can be developed in any part of any country in the world.

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I was then privileged to become Chairman of the national Alzheimer's Society here in the UK. In the reduction of stigma, it is vital that people with dementia and their families are supported and, in addition, empowered to speak in public for themselves. I see this as the power of an Alzheimer society. During my chairmanship, the Society contributed to a quantum leap in awareness about dementia by providing a mechanism through which carers could articulate their needs and provide guidance to others. The backbones of an Alzheimer society are the self help groups which share the aim of improving quality of life for both people with dementia and their families. Our success was, I think, largely due to the fact that we defined our core services tightly, making the dissemination of information our first priority. The involvement of people with business, political, academic and professional backgrounds and not just doctors was and remains key. From a small beginning, the Alzheimer's Society has become one of the best known and most highly respected charities in the UK. The development of a National Dementia Strategy and the recent commitment of our Prime Minister to make the UK the world leader in dementia care and research has taken us many steps further on the path to de-stigmatise dementia. The Alzheimer's Society aim to create 'dementia friendly communities' in which people with this condition are positively included into daily life is a natural progression in the enhancement of people's understanding of dementia.

As a former chairman of Alzheimer's Disease International (ADI), the umbrella organisation for currently 78 national Alzheimer associations, I have been delighted to see the progress made by countries in the less economically developed world where the problem of dementia is growing rapidly as every country starts to have an increasingly ageing population. The recent WHO report written together with ADI this year will help national Alzheimer associations worldwide to reduce stigma. The WHO Report together with other recent reports by ADI would not have been possible without the outstanding epidemiological research carried out by Professor Martin Prince in the UK and an international team of colleagues. They have studied the prevalence of dementia and caring arrangements in many different parts of the developing world. Without such information governments would have no data about numbers and needs for services. With this information, policy makers begin to understand dementia is a disease of the brain that, like all other diseases, has to be recognised, diagnosed and managed as effectively as possible.

So stigma can be reduced in two significant ways. First, high quality effective services for the diagnosis and management of people with dementia and other mental illness and their carers need to be set up. Second, national Alzheimer associations need to be established and maintained to raise awareness, put pressure on governments to achieve policy changes, provide quality information, bring people with dementia and their families together to talk and share problems, and encourage well-known people with dementia and their families to go public to show that they, at least, are not afraid or ashamed.

None of these changes takes place overnight. Every country needs an action plan with close collaboration between government, professionals and the public to achieve, maintain and monitor change. Only then will people with dementia and their families receive the help and support they need and deserve and only then will the shame that results in stigma be finally eradicated ■



# What can we learn from the disability movement?

*Peter Mittler*

I want to suggest that the dementia world should join forces with the disability rights movement - locally, nationally and internationally.

## **Ask yourself:**

What do you know about the disability movement in your country? Do organisations for different groups of disabilities work together to lobby governments to achieve change?

Do people with dementia in your country benefit from legislation and policies for other disabled people?

Have people with dementia and their care partners in your country considered making common cause with people with other disabilities? Or is dementia somehow not regarded as a disability because it is associated with old age?

How closely does your national Alzheimer's society work with other disability organisations? If so, is the voice of people with dementia being heard?

Did you know that people with dementia are included in the remit of the 2008 United Nations Convention on the Rights of Persons with Disabilities? The 117 governments that have ratified the Convention so far are accountable in international law not only to the UN but to their own citizens. Has your country ratified it? If so, are people with dementia included in its implementation? Are they and their care partners benefiting?

## **What does the disability movement have to offer?**

The disability movement was launched by people with mobility impairments but has now broadened to include many others with a wide range of physical, sensory, mental health and intellectual impairments. Working locally, nationally and internationally, it has successfully campaigned for basic human rights and participation in society, as well as access to buildings, public transport, health care, education, employment, recreation and leisure. Furthermore, it has consistently opposed all forms of discrimination and segregation, including institutions, isolation in the community, poor quality care and degrading terminology and practices. Above all, it has insisted on the right of disabled people to be heard: Nothing About Us Without Us has been its watchword; people with dementia and their care partners should find it useful too.

Many years ago, people with intellectual disabilities were not considered able to speak for themselves. From the 1950s, parents began to form local, national and international associations to campaign for recognition for themselves and their children. Many of them were very successful in influencing governments to develop services and supports. But as time went on, their sons and daughters began to form parallel self-advocacy associations of their own. Many were elected or appointed to decision-making bodies, including the UN committee that spent five years negotiating and drafting the UN Convention.

## **Thinking globally**

Once the Convention was adopted by the UN, the needs of disabled people received more priority. All the UN agencies pressed national governments to take action and to make sure that disabled people were included in UN and World Bank development projects and funding. This has now been followed by the excellent global report on dementia prepared by WHO in partnership with Alzheimer's Disease International, shortly after WHO published a separate global report on disability. The whole UN system is currently under pressure to give much higher priority to dementia as a global challenge.

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*Peter Mittler is Emeritus Professor of Special Needs Education at the University of Manchester, England, former President of Inclusion International and a UN consultant on disability and education.*

Most of the articles of the Convention are directly relevant to people with dementia. These include: respect for privacy, home and family, adequate standards of living and social protection, supported decision-making, access to justice and equality before the law, freedom from exploitation, violence and abuse.

### **Health warning**

UN reports and supports are invaluable but only if they lead to a better quality of life and services for people with dementia at national, local and community levels. Many years of working with the UN have taught me that there is a huge gap between rhetoric and reality where people with disabilities are concerned and that the needs of some groups are at risk of being overlooked, particularly those with intellectual and mental health impairments. People with dementia and their advocates will need to be exceptionally vigilant and proactive in ensuring that their voice is heard and heeded.

The good news is that implementation and action at national and local level are much more likely if pressure for change comes from civil society — that means all of us working in partnership. We can make a start by making sure that people with dementia are included in national and local plans to implement the UN Convention ■





## My career with stigma and dementia

*Myrra Vernooij-Dassen*

As a medical sociologist and a curious person, thirty years ago I wanted to do scientific research. I was happy to be invited to perform a study on day care for dementia patients. However, I was also a little bit afraid to be confronted with the problems of dementia patients and their families. I did not feel particularly attracted to dementia problems; in fact, I preferred to avoid them. Being young and taking care of my little daughters, it was easy to live in another world.

I started with little knowledge of dementia and shared some common views about it. At that time, people with dementia were considered not to be aware of their disease. This was a comforting thought. I was unhappy with the first colleague who told me that people with dementia were aware of their problems and condition. However, knowing this opened the door to new approaches. I decided I had a lot to learn about dementia and the best way to do this was to talk with people with dementia and their families. It took some courage, but I left my desk and did many interviews. I was lucky that my fellow researcher, Anneke van der Plaats, was a medical doctor working in a day care centre. She liked to share her daily care experience and we took the time to look at the difference between practice and theory. Our favourite theoretical models were the family crisis and family support models of Bengtson and Kuypers. These discussions shaped my life as a researcher. I became fascinated by studying the secrets of life as expressed in the confrontation with dementia. How can people deal with such a disease? What can we learn from them and how can we support them? After many discussions we decided to translate Bengtson and Kuypers' family crisis model into the sense of competence questionnaire, and the family support model into an intervention to be tested in a randomised controlled trial.

Research focused on problems. You get what you ask for when you use questionnaires. You don't get answers to questions that you don't ask. By asking different questions, we confirmed the stigma that life with dementia is nothing other than a big problem that should be avoided or solved. Many colleagues who are trying to find a cure for dementia still have this opinion. Some campaigns by Alzheimer societies also portray dementia as a disaster. They focus so much on raising attention for the dementia problem that they overlook the fact that they are frightening people and increasing stigma instead of reducing it. This frightens the public and deprives people dealing with the disease of hope.

My 'stigma career' got a new impulse. One morning a woman unknown to me came to my room at the university and asked whether I wanted to analyse the diary she was writing about her sister who had been diagnosed with dementia. This diary opened my eyes to how life could continue despite the disease. The patient enjoyed having dinner with her sister and visiting historic places. There were severe problems, but there also was pleasure. The stigma that persons with dementia had no capacity for pleasure was challenged. Again my view on dementia changed. I became less frightened. And this was at the right time.

My mother-in-law's behaviour profoundly changed. The family was confused and did not know what to do. My husband told me that I was now the expert. OK. I looked at my thesis and decided that we should do what my theoretical model recommended: get a diagnosis and find someone who can communicate the diagnosis and its consequences. The very skilful psychologist knew how to deal with a family disagreeing about what was happening. He also knew how to communicate with my mother-in-law. He respected her and strengthened her dignity, while being quite clear about the situation. He helped her to accept the situation and to hand over her tasks. This worked very well. It was a good start to three years of living with dementia. We had a good life, with her and my

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father-in-law enjoying the last years of their shared life. The knowledge gained from the diary and my own study helped us. I was convinced that it was possible to have a good life with dementia, if you could find the right approach.

This optimism was precious, because there was more to come. My own mother got the disease. I knew it was possible to talk about dementia. I did once. She lamented having the disease and was aware of her deficits. We both cried. Then she stopped crying and said: time for coffee. That was how I knew her. During the disease, we treated our mother as our mother and, despite all the difficulties, she continued to be the lovable mother she always had been, until the very end, six years after the diagnosis. We took her everywhere she wanted to go, we told her friends about it and we were often amazed about how well she was functioning. And how witty she was. My husband once came back from a visit to the cemetery. He told my mother that he enjoyed the quiet atmosphere. 'These dead people do not say much,' replied my mother. We enjoyed being with her and very much appreciated her efforts to continue being our mother.

In my personal life, I owe a lot to my knowledge of dementia and the power of what we call psychosocial interventions (for example, talking therapies or education programmes). Not only the research evidence which underlines their value, but this approach maintained the quality of life of my mother-in-law and her family and my mother and her family. I benefited twice.

My career with stigma started with the idea that dementia patients are unaware of their problems and have no capacity for pleasure. This is not unusual. Even professionals working with dementia patients can have these ideas. My PhD student, Dianne Gove, studied general practitioners' perceptions of dementia, and their perceptions of the public's perceptions. Perceptions can be changed. This is an important task for Alzheimer societies. Within Europe, there are big differences in openness on dementia. In societies with strong Alzheimer advocacy, like the Netherlands and UK, more openness about the disease can be observed than in other societies. Alzheimer societies must use the knowledge gained to fight the stigma attached to dementia and contribute to the emancipation of people with dementia.

People with dementia are neither fully competent nor incompetent. Stigma ignores competence and causes harm by delaying diagnosis and ignoring people's capacity for pleasure and adaptation ■

# Conclusions and recommendations

## Conclusions

There are important conclusions to draw from this Report.

The stigma surrounding Alzheimer's disease and other forms of dementia is an important topic and many people are impacted by it, as shown in both the survey and essays.

## Statistics

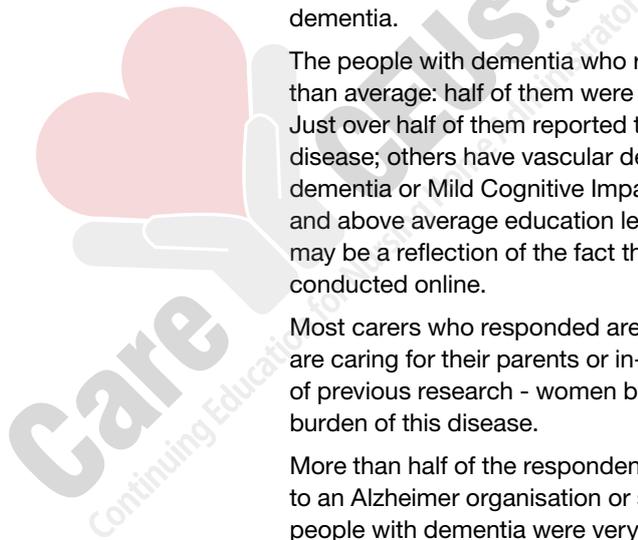
The response to our survey was much larger than expected, with around 2,500 responses from more than 50 countries, the largest portion coming from the USA. Many respondents not only answered the quantitative questions, but also added nearly 300 narratives to elaborate on and explain their responses. In addition, there were more than 900 responses to the narrative questions with personal stories that illustrated experiences, problems and solutions.

Because the survey method provided only for respondents who were able to use the internet (or secured someone to help them), this is not a representative sample. However, it is the first international survey of this size on stigma associated with dementia.

The people with dementia who responded were younger than average: half of them were younger than 65 years. Just over half of them reported that they have Alzheimer's disease; others have vascular dementia, fronto temporal dementia or Mild Cognitive Impairment (MCI). The age and above average education level of the respondents may be a reflection of the fact that this survey was conducted online.

Most carers who responded are female and most carers are caring for their parents or in-laws. This is reflective of previous research - women bear a large part of the burden of this disease.

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. However, both groups agree that politicians have a slightly better understanding of the disease than their constituents.

From the survey, it is clear that some families find it harder to cope with dementia than others. The same conclusion can be drawn from a number of the essays, especially those that were written by people with dementia. 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.

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.

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.

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, and 47% answered that they have made friends who are not connected to the disease. However, many comments in the narratives report current and former friends have pulled away. Thus, people with dementia in this survey may feel relief from stigma when among others in the same situation as themselves.

## Stigma and ageing

The stigma of dementia is intertwined with the stigma of ageing, which is an extra barrier for the diagnosis of dementia. If the assumption is that everyone will become cognitively and physically impaired as they get old, people who are not impaired will not want to admit their age, for fear of being stereotyped as being members of the stigmatised group.

## 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 his contribution to this 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 Peter Piot says that we can be cautiously optimistic, but emphasises the dedication that is needed to build effective coalitions to get things done on the scale that is needed.

## 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 quality of life or capacity for pleasure. While the symptoms associated with dementia affect the way a person with dementia interacts with others, and some activities may be inappropriate as a result, there are many activities, sometimes with adjustments to take account of the disability, in which they can participate. Both people with dementia and their family members will benefit from continuing, whenever possible, to engage in as many activities as they can. Moreover, people with dementia should be encouraged to make decisions or partake 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](http://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](http://www.alz.co.uk/worldreport2012)

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

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.

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.

## 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**



**Alzheimer's Disease  
International**

# Alzheimer's Disease International

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations throughout the world. Each of our 78 members is a non-profit Alzheimer association supporting people with dementia and their families.

ADI's vision is an improved quality of life for people with dementia and their families throughout the world. ADI aims to build and strengthen Alzheimer associations and raise awareness about dementia worldwide. Stronger Alzheimer associations are better able to meet the needs of people with dementia and their carers.

## What we do

- Support the development and activities of our member associations around the world.
- Encourage the creation of new Alzheimer associations in countries where there is no organization.
- Bring Alzheimer organizations together to share and learn from each other.
- Raise public and political awareness of dementia.
- Stimulate research into the prevalence and impact of Alzheimer's disease and dementia around the world.

## Key activities

- Raising global awareness through World Alzheimer's Month™ (September every year).
- Providing Alzheimer associations with training in running a non-profit organization through our Alzheimer University programme.
- Hosting an international conference where staff and volunteers from Alzheimer associations meet each other as well as medical and care professionals, researchers, people with dementia and their carers.
- Disseminating reliable and accurate information through our website and publications.
- Supporting the 10/66 Dementia Research Group's work on the prevalence and impact of dementia in developing countries.

ADI is based in London and is registered as a non-profit organization in the USA. ADI was founded in 1984 and has been in official relations with the World Health Organization since 1996. You can find out more about ADI at [www.alz.co.uk](http://www.alz.co.uk).



“This course was developed from the document: World Alzheimer Report 2012: Overcoming the Stigma of Dementia – by Nicole L. Batsch, Mary S. Mittelman, Alzheimer’s Disease International.”