

A compendium of essays:

# **New perspectives and approaches to understanding dementia and stigma**



**Edited by**

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# Acknowledgements

We would like to express our heartfelt thanks to everyone who contributed essays, without you, this Compendium would not have been possible. We would also like to extend a personal thank you to Professor Hugh Perry who not only conceived the idea for this project, but actually made it happen through his enthusiasm and fundraising ideas. In terms of our 'informal steering committee', we are hugely grateful to Dr Catherine Moody from the Medical Research Council, Dr Matthew Norton from Alzheimer's Research UK and Dr Doug Brown from the Alzheimer's Society for their comments, direction and support throughout the entire process.

We would also like to thank Pfizer, the Medical Research Council, Alzheimer's Research UK and the Alzheimer's Society for sponsoring this project and Harry Ward for the design and production process of the Compendium. Please see Annex II for further information on the organisations involved.

Please note all the opinions expressed in the essays are the authors' own, however all errors and omissions are our own. If you have any comments or feedback on the Compendium, please do email: [sallymariebamford@ilcuk.org.uk](mailto:sallymariebamford@ilcuk.org.uk).

# Foreword

**Baroness Sally Greengross, Chief Executive, International Longevity Centre-UK; Co-Chair, All Party Parliamentary Group on Dementia and Professor Alistair Burns, National Clinical Lead on Dementia, Department of Health.**

Dementia currently represents one of the greatest challenges to our economic, health and social care landscape. With no known cure and with limited treatments available, dementia is redefining our individual and collective experience of ageing, irrevocably changing the lives of ageing citizens across the world. All too often, particularly in the news and common parlance, we hear negative comments and conversations linked to dementia based on cost and consumption, with limited attention focussed on personhood and person centred care. As a society arguably we also need to focus on how we respond to people with dementia in terms of their everyday treatment and experiences and how as a society we balance care and protection with enablement, empathy and empowerment.

We know in many societies that there are strong associations with ageing and stigma and for those with dementia, it seems many are subject to a 'double jeopardy'. While this stigma to a degree is acknowledged and recognised in some communities, we still have much to understand about why dementia remains outside the realm of acceptable everyday conversation even as the profile of dementia rises. That is why we are so pleased to endorse this Compendium, which brings together a range of insights and experiences to explore what may be the basis of this stigma, what are the implications for the individual with dementia and for their families and friends and looking to the future what actions and interventions are required to reduce stigma and promote a positive awareness of dementia across all communities.

We are all on a journey and it is evident particularly at the global level, we have many miles to travel. Reading one of the contributions in this Compendium by Marc Wortman from Alzheimer's Disease International, he suggested that 75 percent of participants of people with dementia and their families interviewed thought that there was a stigma around people with Alzheimer's disease. Someone from the USA said: "*People barely dare talk about it. I have survived the disease, cancer. At that time, people constantly asked how I was doing. Now that I have got Alzheimer's*

*disease, nobody asks.*” Stigma can manifest itself in many forms from discrimination, ignorance, isolation to outright abuse, maltreatment and in some cases even death. Reading such reports clearly highlights that we need to understand dementia and stigma across different cultures and country contexts to lessen the negative effects of it.

This Compendium represents an important milestone in this quest and we are pleased that some of the major players in dementia research and policy have come together to address this issue. The range of articles included help to identify the priority areas for future research and some of the main challenges faced. However further ways of raising awareness and tackling dementia must be sought and we need to continue to work to help deliver a brighter future for people living with dementia, and their families.

# About this compendium

## Context

Over the last decade in the UK, awareness of dementia and support for people with dementia has been at the forefront of political attention and debate. The UK arguably has become a world leader in pushing forward the need to respond to the challenges of a growing number of people with dementia. Following on from the 2013 G8 Dementia Summit hosted in London, which aimed to build an international consensus of countries working together on dementia, the World Dementia Council met in May 2014 to stimulate the innovation and development of life-enhancing drugs, treatments and care for people with dementia within a generation. However, despite the rising profile of dementia in public discourse, the stigma associated with dementia remains an apparently intractable problem, pervading many aspects of life for people with dementia and their carers, and hindering progress in diagnosis, treatment, care and prevention of dementia.

Studies have highlighted the damaging effects of stigmatisation for a range of health problems as well as dementia. The stigma for dementia can take many different forms, including a lack of priority given to the individual's quality of life or other medical conditions because of their dementia diagnosis and a belief by some in society that the lack of a cure for dementia means that it should not be an area of attention for highly-skilled medical interventions and research funding. Fear of being stigmatised may also result in self-regulated exclusion, such as through avoiding a diagnosis<sup>1</sup>, which may prevent people from planning for the future, or accessing treatments available to improve symptoms or slow down the progress of the disease.

As well as dementia, people may have a number of other stigmata; stigma against age and mental health are just two examples. People with mental health problems for example report particular problems with stigma; 87% of people with mental health problems say that stigma and discrimination have a negative effect on their lives<sup>2</sup>. Attitudes also remain that dementia is, and should be accepted as, an inevitable part of the ageing process. Given that multi-morbidity is increasingly the norm for older people with dementia, this group may also face discrimination and stigma associated

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<sup>1</sup> The Alzheimer Society of Ireland (2006) Perceptions of Stigma in Dementia: An Exploratory Study. <https://www.alzheimer.ie/Alzheimer/media/SiteMedia/PDF%27s/Research/Stigma-in-Dementia-Report.pdf?ext=.pdf>

<sup>2</sup> Time to Change (2008) *Stigma Shout* <http://www.time-to-change.org.uk/sites/default/files/Stigma%20Shout.pdf>

with other medical conditions. Additionally, some symptoms of dementia are stigmatised in and of themselves such as, for example, incontinence<sup>3</sup>.

As a result of population ageing – and particularly the enormous growth in the ‘oldest old’ in our society, and the corresponding increased likelihood of having dementia as one ages<sup>4</sup> – the number of people with dementia is growing. By 2021, there will be a million people with dementia in the UK alone<sup>5</sup>. These people will live under the shadow of the stigma associated with dementia if more is not done to tackle stigma and its causes.

## Our rationale

The issue of stigma is widely acknowledged as a serious challenge for people with dementia and their carers at the individual, family and societal level, and as noted above serves as a barrier to access care, support and treatment. However, limited attention has been focussed on the origins of stigma and stigmatisation. In response to this, the Medical Research Council, Alzheimer’s Research UK, Alzheimer’s Society and the International Longevity Centre-UK, with the support of Pfizer have come together to stimulate the conversation around the causes of the stigma faced by people with dementia, and to move towards addressing the roots of stigma in our collective responses to it.

Our overarching goal is to shed greater light and insight on the causes of stigma and explore this from a multidisciplinary perspective. Until we fully understand the origins of stigma and its various manifestations, developing an evidence-based and cogent response to dementia will remain elusive. By addressing the underlying causes of stigma, education and information can become more effective and may potentially remove the stigma and associated discrimination.

In order to explore this subject further, we decided to bring together, at the national and international level, some of the leading minds from the field of dementia and other relevant health conditions to share their expert opinions and views. We had a two-pronged approach to this project, to hold a high level discussion in the House of Lords, see below, and then develop the themes that emerged from the discussion to form this Compendium, with contributions from across academia, the public and private sector and the voluntary sector.

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3 Benbow, S. and Jolley, D. (2012) Ethical Perspective. Dementia: stigma and its effects. *Neurodegenerative Disease Management* April 2012, Vol. 2, No. 2, Pages 165-172

4 See, for example, Lobo et al (2000) Prevalence of dementia and major subtypes in Europe: A collaborative study of population-based cohorts. Neurologic Diseases in the Elderly Research Group. *Neurology*. 2000;54(11 Suppl 5):S4-9.

5 Alzheimer’s Society (2014) Statistics [http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=341](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=341)

## Stage 1, Expert input

In early 2014, 70 experts in dementia and other health-related conditions were invited to a high-level discussion in the House of Lords to discuss the issue of stigma associated with dementia, and request their input on what direction to take, in terms of research, education and policy, to ameliorate the situation. At this dinner, convened speakers with expertise in neuroscience, ethics and those living with dementia set the scene, before open discussion and questions from all attendees (See Annex I for the list of attendees).

Attendees were provided with a contextualising brief, and were asked to fill in a questionnaire with the following questions:

- What do you think are the underlying reasons or factors that contribute to the stigmatisation of people with dementia and their carers?
- What would be the benefits of scientific research aimed at understanding the neurobiological causes of the stigma of dementia?
- What do you feel is the individual and wider impact of such negative and discriminatory attitudes? For example, individuals or families not seeking a diagnosis?
- What would be the added value to health or social care if we reduced stigma? For example, timely diagnosis leads to greater support and possible delays to admission to residential care.
- What can we learn from other groups that are or have been historically discriminated against; for example, people with disabilities with regard to stigma?
- Do we have enough evidence to fully understand the motivations, nature and current impact of stigma on dementia?
- What should happen next and by whom?
- What, if any, public awareness campaigns, educational programmes do you feel would be most effective in tackling this issue?

We were extremely pleased and grateful for the enthusiasm expressed by our attendees and the range of responses we received and accordingly we have summarised some of the emergent themes from the questionnaires into a chapter to form part of this Compendium. The feedback we received on the evening has also helped shaped our overall approach with regards to the structure and content of the Compendium.

## **Stage 2, Compendium of essays**

This Compendium, as noted above, brings together different perspectives on the stigma associated with dementia. It seeks to probe and better understand the roots and causes of this stigma, and armed with this greater understanding, to suggest ways forward to address these causes. In compiling this Compendium, we have sought to include voices with different expertise. We cover personal experiences with dementia, from a carer and a clinical perspective. We hear expert voices on the ethical and neurobiological aspects of this issue, as well as the policy context, and we explore what we can learn from overcoming the stigma associated with other health problems, such as AIDS.

In our increasingly globalised world, we wanted to ensure that voices from outside the UK were heard, so we have included contributions with European and worldwide perspectives, as well as the specific challenges for minority ethnic groups to tackle stigma. We end with a focus on what the future direction of travel should be, and how we can take action together to progress this agenda further.

# Chapter 1: Personal reflections

## Paul's story

*Paul, 53, had to give up his career as an IT financial services consultant in 2012 when he was diagnosed with Posterior Cortical Atrophy (PCA). This rare form of Alzheimer's disease typically begins with visual difficulties. Although the symptoms of PCA prevent Paul from doing many day-to-day things, he still enjoys running, with the help of guide runners, and has found a new talent in painting. He lives with his wife and two daughters. Paul said:*

“When the symptoms first started I didn't understand what was happening to me. I was working full time as an IT financial services consultant but found it increasingly difficult to read and judge distances. One day when I was in the office I turned round after talking to a colleague and just didn't know where I was or where to go. I'd worked there a long time and knew the layout well but suddenly didn't recognise anything – It was very scary.

It felt as if my glasses had been smeared with Vaseline and I had many unsuccessful trips to the optician. Although I tried to put on a brave face at work, inevitably I started to make mistakes, which made the situation even more distressing. My employer was understanding but assumed I was under stress and suggested I take some time off. They also arranged for me to have some counselling.

My wife Alison thought I was having a nervous breakdown and persuaded me to see my doctor. Initially he put the symptoms down to stress and prescribed some medication to calm me down. But as things were no better after two weeks he referred me for some neurological tests. The diagnosis of Posterior Cortical Atrophy followed.

Although it was a shock, I was a relieved to know what was wrong. I was keen to be open and tell my friends. But some have dropped by the wayside since then, which is disappointing. I suppose it's because they don't understand much about Alzheimer's, just as I didn't before I got the diagnosis. I think it's the fear of being confronted by it, knowing how to react and what to say. Even some members of the family have drifted away. But in other cases it's made relationships stronger.

At first when I was out in public places I found people could be very impatient. They would push past me if I was a bit slow or 'tut' if I got in

their way. Nowadays, I carry a white stick to indicate I have problems with my sight. Although I've had to give up my job, stop driving and need help with many day-to-day things, I like to concentrate on what I can do rather than what I can't. I can still run with the help of guide runners, I get a lot of enjoyment from my music collection and have found a new talent in painting. I also like to keep up with the news, discuss current affairs and put the world to rights. Although the right words don't always come to me easily, Alison and my daughters help to fill in the gaps.

My diagnosis has closed many doors to me but I've been pleased to find it's opened others. For example, my local running club has taken me to heart and I've made many new friends as a result. It's been a godsend because, having been used to working full time I now have a lot of time to fill. There is a need for more support and activities for people who are affected by dementia at an early age – everything is geared to the older generation

I would like to see more public awareness of Alzheimer's and other dementias and also make people aware that it doesn't only affect older people. I would also like to see more awareness in the work place. It would have been impossible for me to continue in my job but in some cases people may be able to carry on working at a different level.

The only answer to dementia is research and I plan to do everything I can to help Alzheimer's Research UK find the preventions and new treatments so urgently needed.

*Source: Alzheimer's Research UK – September 2014*

# Sylvia and Bob Kahn's story - overcoming the stigma of dementia

*Sylvia is a retired solicitor; and Bob is a medical writer. They have five grown-up children and 14 grandchildren, one of whom is a Dementia Champion. Since 2012 they have made some 15 joint presentations about living with dementia.*

Bob: Sylvia, what has been your experience of stigma during these last seven years as you have moved through Mild Cognitive Impairment to vascular dementia to Alzheimer's disease in January 2011, confirmed by several brain scans?

Sylvia: I don't think that people can tell that I have Alzheimer's by looking at me or talking to me. I don't.

B: That's true for short conversations, but your style of walking and the expressions on your face are distinctive. I looked up the origin of the word "stigma" and found it comes from the Greek word *stizien* meaning "to mark with a tattoo," and in that sense you are not marked with dementia. However, the dementia is certainly affecting how you live.

S: Yes, I chose to give up my job as a solicitor; and I was required by the driving license authority to give up my absolutely clean driving license, which was fair enough, because you can't have those of us with dementia driving along the road not being able to control their vehicles properly.

B: Not working and not driving are consequences of dementia, but not, I think, part of the stigma of having dementia.

S: Well, I think in a way they are part of the stigma of dementia. In this culture, not working and not driving are often viewed as a shame or social disgrace—which is precisely the definition of stigma.

B: OK, fair enough. Perhaps the first kind of stigma that people with dementia encounter is the fear of others to relate to them in any way.

S: Yes, those of us with Alzheimer's are often deeply hurt when people are afraid to talk to us. Perhaps during the conversation we will repeat ourselves. So what? That's life. You can still talk to us; and you may be surprised by how incisive some of us can be.

B: Agreed. We can each discover the reasons behind the behaviour and emotions of people with dementia. Being with you, the question in my mind is often "*When* in time are you in your relationship to your past?"

S: Well, when you ask a question, I can no longer give a quick, coherent answer. I have to think about it much more. I do live in a *general* muddle, but it's spasmodic; and I'm never sure when a *particular* muddle is going to erupt.

B: Precisely, and that is the behaviour that leads those of us who do not yet have dementia to stigmatize those of you who do.

S: Why should you stigmatize us? We didn't ask for the dementia. It's not a crime.

Earlier, I was sitting looking at the raindrops on the window pane. They were large drops which distorted my view of the houses on the opposite side of the road. That is my experience of dementia – a blurring of reality, yet reality is still there, even if I am not fully aware of it.

B: Right, in my opinion you still have the ability to distinguish between reality and unreality. However, in the late afternoon and early evening as the sun goes down the distinction between the past and the present can become blurred. You do often experience “sundowning.”

S: Sniff!

B: What do you mean, “sniff”?

S: Well, you have to be honest and become aware of time changes, especially if they are starting to affect you.

B: Yes, your usual honesty is helpful, because other people need to know that in the late afternoon and early evening people with a moderate level of Alzheimer's do experience considerable confusion about what is in the past and what is in the present.

S: It would be helpful if people knew more about “sundowning” and the experience of having Alzheimer's, but most people don't want to know. They turn away (or in your case, pick up a book) and continue with their lives, ignoring you.

B: Hum! Perhaps the most difficult stigma associated with dementia is the stigma that people with dementia experience within themselves—that they are (to use your phrase) “no good”—that they can no longer make a significant contribution to society.

S: Yes, I do want to help others and to make a contribution to society, if possible.

B: These conversations can help others. I am confident that both of us

can overcome the stigma of dementia, both within ourselves and within other people.

S: The fact is that you give me a lot of strength because you are confident that I can manage to live well with dementia and not let it dominate our lives.

B: That is a beautiful response. I do try hard to communicate to you that we can still live lives of considerable purpose, overcoming both dementia and the stigma of dementia.

### **Suggestions for further reading**

Albert Jewell (ed.), *Spirituality and Personhood in Dementia* (London: Jessica Kingsley, 2009), especially Clive Baldwin, "Personhood, Personalism and Dementia: A Journey of Becoming," pp. 186-197

Anne Karpf, *How to Age* (London: Macmillan, 2014)

Margaret Lock, *The Alzheimer Conundrum: Entanglements of Dementia and Aging* (Princeton NJ: Princeton University Press, 2013)

Elizabeth MacKinlay, *Ageing, Disability and Spirituality: Addressing the Challenge of Disability in Later Life* (London: Jessica Kingsley, 2008), especially Michael Anstey, "Spiritual Reminiscence and Narrative Gerontology: Jacob's Wrestling with the Unknown (Genesis 32)," pp. 106-117

G. Allen Power, *Dementia beyond Disease: Enhancing Well-being* (London: HPP/Health Professions Press, 2014) [with 27 references to "stigma" in the index]

Dave Pulsford and Rachel Thompson *Dementia: Support for Family and Friends* (London: Jessica Kingsley, 2013, p. 164)

Marty Richards, *A Reciprocal Approach to Caregiving and Care Receiving in the Complexities of Aging, Illness or Disability* (Woodstock, VT: Skylight Paths, 2009)

Graham Stokes, *And Still the Music Plays: Stories of People with Dementia* (London: Hawker, 2010, 2nd ed.) Karen Kissel Wegela, *How to Be a Help Instead of a Nuisance: Practical Approaches to Giving Support, Service & Encouragement* (Boston: Shambhala, 1996)

Lucy Whitman, *Telling Tales about Dementia: Experiences of Caring* (London: Jessica Kingsley, 2010)

## Keith Oliver's story

*Stigma and dementia, a perspective from a person with Alzheimer's disease.*

Whether real or perceived stigma is a very significant issue and concern for many people affected by dementia, both those living with it and those living with us.

One could say that stigma exists in a range of ways within our society not just connected with dementia, but where it is particularly noticeable is when one thinks there is stigma around being old, around mental illness and around dementia - usually those with dementia fall into all three categories, and those people termed as having young onset often also experience dis-belief and mis-trust around their difficulties.

Everyone with dementia is different, and there are many different types of dementia. What though is consistent is the progressive nature of the condition, and the fact that currently there is no cure available. Consequently, this combination contributes to fear, both from those affected, and from society generally. In addition there are mis-conceptions, half-truths and mis-understandings, often fuelled by a headline grabbing media which serves to reinforce negative perceptions which in turn feeds views associated with stigma.

Fear is I feel at the root of this issue. Fear from the person with dementia that their life is changing for the worse, and that there are no interventions and/or support to help them to live as well as possible, and that they are somehow to blame for the negative changes in their behaviour and personality. This often provides challenges to loved ones, family and friends who at times reinforce the stigma, often unwittingly by talking about their "declining," changing or now more challenging loved one/friend, often without understanding the changes which the person is confronting. Stigma then obstructs the person's ability to continue to make useful contributions to family or the broader society. One early casualty of this is the person's self esteem which is hard to recover once tipped into downward mode. People don't always know what to say to the person with dementia - do they feel sorry for them, do they fear upsetting them, do they fear an aggressive/challenging response to something they may say or do? The stigma is internalised (often in both the person with dementia and their loved one/s) and then it "feeds on itself," leading to someone who previously may have been trying to live well, feeling now depressed, helpless and socially excluded.

## **All though should not be doom and gloom!**

With support, understanding and tolerance, stigma can be kept at bay and dealt with as rationally as possible. The Dementia Friends initiative is potentially a powerful force in raising awareness, and in turn friendly support for those of us with dementia. Service User involvement groups such as those co-ordinated by DEEP give people comradeship and a real sense of continuing to make a useful contribution to society. The Alzheimer's Society through its service user involvement plan and associated activities encourages people with dementia to live well in spite of difficulties being confronted. The Society is also committed to working with the media to try and reduce stigma in its portrayal and language used to describe dementia and those living with it. The Dementia Friendly Communities initiative is starting to make a real difference in some parts of the country.

Although this may appear to be written in the second person, these views are based on the real experience of one person, me, but not only my experience but the experience of many people sharing this "journey" who I have been privileged to meet in the past four years since I was diagnosed with Alzheimer's disease.

# A cure for stigma

## Dr Jack Watters

*Dr Jack Watters is Pfizer's Vice President for External Medical Affairs, responsible for relations with medical societies, academic institutions and government health bodies around the globe. Dr Watters has also represented Pfizer on matters of corporate responsibility and human rights, especially relating to raising political will for the plight of people with HIV/AIDS and the older citizen. He joined Pfizer in 1994 and was an architect of the landmark Difflucan Partnership Program which is now active in sixty of the world's least developed countries.*

Dementia stirs fear in the hearts of us all. It is a frightening condition and sheer terror often drives people from knowing the truth. Being given a diagnosis of early dementia is a devastating life event for patient, family and caregivers alike and it is understandable that, given a choice, most people would rather not hear this, especially since treatments today cannot cure any of the myriad forms of dementia and only in select cases can its progression be delayed. While clinical trials have proved disappointing to date in finding a cure, we are gathering more and more reliable data on the numerous factors and behaviours that cause dementia and this information can guide us in our attempts at prevention. I also believe that with early and accurate diagnosis much can be done to prevent the progression of the disease and its attendant ravages can be greatly reduced.

I am reminded of the early days of the AIDS crisis in the 1980s when the popular wisdom was *'it's better not to know'*. This has, of course, changed with the advent of highly effective treatments but in those dark days we asked *ourselves 'why would we want to hear this news, especially when there is nothing we can do?'* But there is always something we can do. With both conditions, one of the main reasons for not wanting to know the diagnosis is the fear of being marginalized, losing one's job or insurance, being ignored or misunderstood, and watching formal and informal support disappear for no good reason. In other words, STIGMA, and only by addressing such understandable if irrational behaviour head-on can we expect to prevent it and perhaps cure it too.

I believe that if we bring dementia out of the closet we can drive stigma away. Of course, this requires open discussion, honesty, widespread dissemination of accurate information as well as sensitivity, compassion

and, above all, courage.

I shall never forget attending an incredibly moving session on dementia at the 2012 Cheltenham Science Festival. The professionals talked knowledgeably about the epidemiology and the science, as one would expect, but most articulate of all was a woman in her sixties who had been told that she had the signs of early dementia. Jennifer Bute, herself a doctor, described with devastating frankness what she had noticed, how she had become aware of slight changes in the content of her speech and lapses of memory, and how she knew what the likely diagnosis was. This was subsequently confirmed by her doctors. Dr Bute did not see herself as a victim, nor did she appear to feel sorry for herself. Rather she saw the early diagnosis as an opportunity to live each day to the fullest while taking charge of her own health. This combination of fortitude and personal engagement left no room for fear of stigma. Dr Bute had far too much living to do and there is a lesson for us all here.

Of course, this is not easy and Dr Bute was the first to recognize the difficulties she continued to experience. But so much of it can be prevented. People with dementia often have complicated medical histories with many concurrent illnesses – so-called multiple morbidities. Diseases like high blood pressure, diabetes and heart disease can all be treated very effectively and, in so doing, the patient's quality of life can be greatly improved. But this is only possible if the primary diagnosis is made and the medical team is on the lookout for these other conditions. That is why general practitioners need to be trained, empowered even, to make the initial diagnosis as early as possible, and by having at their disposal the services to support the new patient and family through the full natural course of dementia.

As a doctor, I believe that prevention is always better than a cure and we have so much knowledge available to prevent not only the condition of dementia but also the stigma associated with the diagnosis. But we must all get involved – doctors, nurses, pharmacists, care-givers, social workers. The media has a vital role to play in this too and our legislators can take the lead by publically recognizing our increased life expectancy as the greatest social achievement of the past hundred years. Our goal must be to ensure that we all enjoy the longest possible healthy life expectancy while recognizing and embracing dementia as a fact of life. Let's speak out against stigma; let's make it unacceptable.

I have no doubt that the discovery of effective pharmacological treatments

for dementia which can either prevent or cure the disease will remove the stigma overnight, making it a thing of the past, like AIDS or TB, and we are working hard in laboratories across the globe to find that elusive gene, molecule, receptor, physiological marker or mechanism that will make this a reality. Until this happens, we are all responsible for curing stigma.

# A carer's perspective of stigma and dementia

## Lesley Finlay

*Lesley Finlay is the primary carer for her father Ken who is 81 and was diagnosed with Alzheimer's disease in 2011. Lesley lives in Londonderry, Northern Ireland and works as a Health Improvement Officer for her local Health and Social Care Trust.*

*Until Ken's diagnosis he was living a fully independent life, undertaking all daily living tasks and socialising without requiring any support. Although he remains living alone in his own home, Ken now requires support and encouragement to undertake many daily living tasks and to participate in social activities outside his home. This support is largely provided by Lesley and her brother Stephen, and by the Alzheimer's Society who provide a home support service twice per week.*

*Ken's experience of the world around him has changed considerably since his diagnosis. He becomes anxious and frustrated as a result of his dementia and the reactions of others towards him. However, Ken remains a vibrant and sociable person whose greatest gift is to make people laugh.*

When someone receives a diagnosis of dementia, it does not follow that overnight they no longer want to go to work, socialise, take the bus, go to the cinema or conduct their own financial affairs. A person with dementia still has skills, preferences and feelings. They still have a voice. Stigma can try to silence that voice.

Until his diagnosis with Alzheimer's disease at the age of 79, my dad lived entirely independently. He did all his own banking, shopping, cooking and cleaning. He took the bus to visit friends, walked to Church every Sunday and attended social activities in his local community centre.

When my dad was diagnosed with dementia he didn't suddenly become unable to undertake many of these activities, but his interest and confidence quickly dissipated. He now requires much more support and encouragement to undertake daily living chores and engage in social activities.

Research tells us that many people with a diagnosis of dementia feel they are forced to give up work and suffer depression, feel socially isolated, lack confidence and experience feelings of poor self-worth. I would question how much of this is due to the pathology of dementia, and how

much is a result of the stigmatisation of this disease.

As someone living with the reality of dementia on a daily basis, I welcomed the focus on dementia at the recent G8 Summit. It is also encouraging to hear the Government's commitment to a dementia awareness raising campaign and the Government and Medical Research Council's investment into research, treatments, and potentially even a cure for dementia.

In the voluntary sector, the Alzheimer's Society is also championing dementia-friendly communities. It is this concept which most excites me. Through experience, I feel passionately that the simplest changes can make the greatest difference to someone with dementia and their family and carers. Part of dementia-friendly communities is around the creation of dementia friends - volunteers who commit to doing small things that can make a significant difference in the lives of those living with dementia.

This is part of a wider agenda of increasing public awareness of dementia. We need to educate people on what dementia is, how it affects people and how to interact more positively with a person with dementia.

When I tell people my dad has dementia, the focus is on memory problems. But the impact of dementia is much more than being forgetful. It can affect recognition, behaviour, mood, social interactions, communication, physical and mental health, comprehension, confidence, personality and inhibition. It impacts family life. It creates carers who are stressed and emotionally drained. It debilitates the sufferer. And then it kills.

People with dementia risk being marginalised in their communities: socially isolated, pigeon-holed, talked down to and labelled. Yet people with dementia can live independently for many years with support. With the *right* support, they can lead active and fulfilling lives in their local communities.

The stigma associated with dementia can result in many individuals and families failing to acknowledge the symptoms, seek diagnosis or availability of treatment as well as the practical, emotional and financial supports. We need to educate the general public and particularly our service providers - financial institutions, public transport, theatres, retailers, leisure facilities, local authorities, and health services. We need people to understand that the impact of dementia has a ripple effect. It not only affects the person who is diagnosed, but friends and family, local communities, regional and national organisations and service providers.

We need more dementia friends in our communities and service providers who are dementia-friendly champions.

My dad no longer enjoys the same level of independence or range of activities as he did prior to his diagnosis, but his quality of life remains good. He remains living independently at home because, without realising it, the community in which he lives has rallied round to support him. He has many dementia friends. The taxi office opposite has our contact numbers so when he tried to take a taxi and got lost it worked out where to take him and alerted my brother. The milkman knows to go into the house to check his milk levels so my dad doesn't run out. The shopkeeper reminds him which paper he prefers. The neighbour brings in his bin in case my dad becomes distressed when it appears to be missing. Another neighbour calls to walk him to the lunch club in a local church every Monday as my dad wouldn't have the confidence to go alone. The Alzheimer's Society has provided a Home Support Worker twice weekly to provide company and friendship, taking him out for walks and cups of tea, to help him connect with his local community. These people are all dementia friends.

The role of a carer for someone with dementia is about supporting this person to maintain their independence and to nurture their confidence in continuing to pursue their interests and participate in their local community. The stigma that exists around a diagnosis of dementia and the resulting stereotypes make this a challenge. What is even worse, the affected person can internalise this stigma and feel unable or unwilling to interact in an unsupportive environment. The person with dementia can become marginalised, diminishing their chances of reaching their full potential and hampering their ability to attain happiness and contentment.

The World Alzheimer Report in 2012 identified 10 key recommendations to overcome the stigma of dementia. The first is arguably the most important: educate the public.

Stigma results from lack of understanding. We need to explore how to help people understand. How to reduce stigma. How to create dementia friendly communities. How to empower dementia friendly champions.

# Chapter 2: Understanding dementia and stigma from a multidisciplinary perspective

## What's going on in your head? The neurobiology of stigma

**Neil Harrison**

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Stigma has an extremely detrimental effect on all aspects of the lives of individuals with mental health conditions and those with dementia are at further risk of experiencing implicit ageist attitudes. Within social psychology, understanding the cognitive mechanisms of stigma and associated concepts of prejudice, discrimination and stereotyping and how they impact sufferers' lives has formed an important focus. However, remarkably little comparable research has yet been undertaken in dementia. Addressing this will be critical to optimizing the effectiveness of future strategies aimed at minimising stigma and its impact on individuals living with dementia.

Until the mid-1990's, stigmatising responses were typically determined using complex and often time-consuming self-report questionnaires. However, this approach had two fundamental weaknesses. First, it was very labour-intensive and thus difficult to implement quickly across large populations. Second, and perhaps more importantly, it was recognised that despite reliable engagement, individuals' reports of their own prejudices, biases and stigmatizing responses were frequently at marked variance with their behaviour. As inherently social animals, we are all susceptible to powerful social biases including social desirability bias. These biases likely underpin discrepancies between unconscious or implicit stigma responses and those that we report consciously.

A number of alternate methods have subsequently been developed to address this. Perhaps most useful are the 'implicit' association tasks in

which participants use button presses to rapidly classify words such as student, success, failure, pensioner, to concepts such as good and bad or old and young. These tasks are quick to complete (they can be completed on-line in 5-10 minutes) and have been useful in revealing often surprisingly widespread negative biases towards other stigmatised groups such as those from minority ethnic groups or individuals with other mental or physical health disorders. Though rarely used to investigate implicit negative attitudes towards individuals living with dementia currently, they offer a cheap and simple way of exploring the prevalence of these attitudes across society. They could also serve to highlight to individuals within health and social care sectors any implicit negative biases of their own that may be impacting on the quality and nature of the care they provide.

Though heavily influenced by our socio-cultural environments, stigma, prejudice and discrimination ultimately result from activity within our brains. These attitudes are often deeply ingrained and future efforts to challenge stigmatising responses towards individuals with dementia will benefit from an understanding of their neurobiological basis. For example, brain-imaging studies have demonstrated that when viewing black versus white faces, responses in the amygdala (a small, ancient brain region central to processing emotions) powerfully predict unconscious measures of racial prejudice. Though similar studies have not been completed for stigma and dementia, these findings are important as the amygdala is widely believed to be central to coordinating rapid responses to emotionally salient or threatening situations. It can also alter behaviour in subtle and often unintentional ways.

Brain imaging studies have also investigated how the brain regulates negative bias to stigmatised individuals. These studies have shown that conscious attempts to reduce negative bias towards stigmatised individuals are associated with increased activity within evolutionarily more recent frontal brain regions. However, they have also shown that conscious regulation of stigma responses may be more effortful than other forms of emotion regulation.

Together these studies highlight the deeply ingrained nature of stigma responses that may persist implicitly, even when unidentifiable, at a conscious level. Automatic activation of ancient emotion-processing mechanisms within the brain may underpin this relative persistence. However, the human brain has an extraordinary capacity for adaption and change. More recent studies have demonstrated specific brain networks

that are activated during the conscious regulation of stigma responses. Though recruitment of these mechanisms appears more effortful than when used to regulate other emotional responses, they support the utility of developing future strategies to combat stigma in dementia. Availability of cheap, quick and simple tasks to measure implicit negative biases towards individuals with dementia would support a rapid assessment of the prevalence and severity of these attitudes within society. They could also potentially act as a measure of the effectiveness of stigma-reducing strategies, ultimately helping improve the lives of individuals living with dementia and their carers.

### **Suggestions for further reading**

John Dovidio et al. (2010) Prejudice, stereotyping and discrimination: Theoretical and empirical review. In: Eds. Dovidio JF, Hewson M, Glick P, Esses VM. The Sage handbook of prejudice, stereotyping and discrimination, Sage Publishers: London, UK; p3-29.

Alison Milne (2010) The 'D' word: Reflections on the relationship between stigma, discrimination and dementia *Journal of Mental Health*, 19: 227-233.

Todd Nelson Ageism (2011): The strange case of prejudice against the older you. In: Eds. Wiener RL, Willborn SL. *Disability and Aging Discrimination*, Springer, New York, US; p37-47.

Anne Krendl (2010) The good, the bad, and the ugly: An fMRI investigation of the functional anatomic correlates of stigma. *Social Neuroscience* 1: 5-15.

Anne Krendl et al. (2012) How does the brain regulate negative bias to stigma? *Social Cognitive and Affective Neuroscience* 7: 715-726.

Megan Oaten et al (2011). Disease avoidance as a functional basis for stigmatization *Philosophical Transactions of the Royal Society B*. 366: 3433–3452.

# Stigma: The ethical imperative

**Julian C. Hughes**

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The public consultation at the start of the dementia working party of the Nuffield Council on Bioethics established that in the main society's perceptions of dementia are negative.<sup>1</sup> Dementia is “feared, dreaded, hidden; a form of madness”, which is not understood, which upsets the ability to communicate, and which leaves carers feeling apologetic. People both *under-estimate* the impact of the disease (i.e. it is *just* a question of memory) and *over-estimate* it (i.e. people with dementia get violent). Dementia is accompanied by shame and embarrassment. One anonymous respondent said: “No member of society should be cast onto the scrap-heap of life simply because they are no longer wanted, no longer spend money and no longer vote!” Stigma also extends to include, not just families, but those who *work with* people with dementia.

Similarly, in practice, I recall people with dementia and carers saying how their friends seemed to disappear. One inevitably thinks of Tom Kitwood's “malignant social psychology” and of Steve Sabat's notion of “malignant positioning”.<sup>2,3</sup> Yet some of this stigmatization is *self-stigmatization*: people feel ashamed of themselves. The word “stigma” derives from the Greek word meaning “to prick”: it conveys the idea of being marked or labelled. But people with dementia are often marked with *other* stigmata – those of old age and mental illness – which compound the problems.

The nature and reality of stigma are apparent. Things *are* changing; but they *must* change. This is the nature of the imperative. The Nuffield Council's report stressed that, *on the one hand*, dementia results from a *disease*. It should, accordingly, be given at least as much priority as any other disease in terms of funding for both services and research. In addition, our *attitudes* to people with the condition should be the same as for other diseases: attitudes of concern, compassion and respect; not

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1 Nuffield Council on Bioethics, *Dementia: Ethical Issues*, Nuffield Council on Bioethics, London, 2009. Available via: <http://www.nuffieldbioethics.org/dementia>

2 T. Kitwood, *Dementia Reconsidered: The Person Comes First*, Open University Press, Buckingham and Philadelphia, 1997.

3 S.R. Sabat, *The Experience of Alzheimer's Disease: Life Through a Tangled Veil*, Blackwell, Oxford, 2001.

attitudes of fear, dread and horror. *On the other hand*, in addition to its being a disease, it should also be possible to *live well* with dementia if the right sort of care and support were available.

The imperative to provide appropriate care and support in part stems from the salience of two other components in the ethical framework set out in the Nuffield Council's report. First, we should act in accordance with solidarity. That is, we should recognize our inter-dependence *as citizens* and the rights and responsibilities that flow from that status. Secondly, we should respect the identity and personhood of individuals, even if they have dementia, which will involve taking their values seriously.

It seems to me that the notion of personhood is critical. I would characterize the person as a situated embodied agent.<sup>4,5</sup> The key idea is that of being situated: we live our lives in a context. None of us is understood properly *without* the context: of family, personal narrative, social milieu, cultural beliefs and so forth. This point is the basis of the ethical imperative. By our nature we are situated, which means that we inter-connect. Our autonomy and well-being (both emphasized in the Nuffield Council's report) are predicated on the solidarity – respect for the common good – which *just is* a manifestation of our situated being. Situatedness also means that, in a radical sense, *stigma* must be seen in context.

Stigma is a matter of perception; and perception is something that involves the brain. Accordingly, there must be something biological about stigma. In evolutionary terms, perhaps, we want nothing to do with illness and disability. But I want to propose a cautionary note. Let us grant that perception occurs in the brain. Still, the meaning and significance of *the percept* is in the world. Merleau-Ponty suggests that whilst the body is fundamental to our subjective awareness of the world, the world is fundamental *as the locus*, the place, in which actions have meaning. In the Preface to his book he says: 'The world is not what I think, but what I live through'.<sup>6</sup>

We need to ask what it *means* to be stigmatized. Questions about the *nature* of stigma take us to the world of human beings: the world we all "live through"; the world of meaning and significance in which we are situated.

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4 J.C. Hughes, 'Views of the person with dementia'. *Journal of Medical Ethics*, 27, 2011, pp. 86-91.

5 J.C. Hughes, *Thinking Through Dementia*, Oxford University Press, Oxford, 2011.

6 M. Merleau-Ponty, (1962 ). *Phenomenology of Perception* (trans. C. Smith), Routledge, London and New York, p. xviii. (First published 1945.)

What are the practical implications of these thoughts? As a general point, if we wish to understand any human phenomenon as complicated as stigma, we shall need to take a very broad view. Understanding the person – in a holistic manner – means understanding the psychosocial and spiritual environment; it also means understanding biology, from neuroscience to evolutionary theory. But understanding biology ultimately brings us back to the meaning of things *in the world*. In the end, it seems to me, it is the notion of solidarity that should *erase the mark*, or stigma, of dementia. But human solidarity involves what philosophers have called the “space of reason” in which moral concern (solicitude) and values have a place. We should use all our reason – we are after all sapiential – to enlarge our understanding. But finally it is our situated nature as interconnected and inter-dependent human beings *in-the-world* that provides the ethical imperative to show solidarity with *all* those around us, even if – and perhaps more so if – they have dementia.

# Chapter 3: The impact of stigma for decision-making, diagnosis, treatment and care for the individual

## Earlier recognition of dementia in primary and community care

**Dr Jill Rasmussen**

*Dr Jill Rasmussen is a GP with special interest in psychiatry and neurology. She is RCGP Clinical Champion for Dementia, Strategic Clinical Network SE Lead for Dementia and Commissioning Lead for Mental Health, Dementia and Learning Disability for the East Surrey CCG.*

A convincing body of evidence shows that early diagnosis is beneficial not only to individuals and their families and carers but also to the public at large because of cost-saving to the health service<sup>1</sup>. Despite this evidence and initiatives such as the National Dementia Strategy 2009<sup>2</sup> and the Prime Minister's Challenge for Dementia 2012<sup>3</sup> the mean dementia diagnosis rate in England and Wales of 46% remains well below the target of 66% to be achieved by March 2015<sup>4</sup>. The All Parliamentary Party Group (APPG) report on Unlocking Diagnosis – the key to Improving Lives of People with Dementia - highlighted a range of factors throughout the diagnostic process that act as barriers to the recognition of dementia<sup>5</sup>. A number of these relate to issues in society as well as issues in primary and community care.

Surveys of the public conducted in 2008 suggested that people over the age of 55 fear being diagnosed with dementia more than any other condition<sup>6,7</sup>. The public often consider issues with their memory to be a normal part of aging with the consequence that they delay seeking advice – up to one year in a third of cases and 10% of people never go to their GP because they think that nothing can be done<sup>8</sup>. Unfortunately,

1 Department of Health. *Living well with dementia: A national dementia strategy*. Department of Health, London 2009b

2 Department of Health. *Living well with dementia: A national dementia strategy*. Department of Health, London 2009b.

3 Department of Health. *Prime Minister's challenge on dementia: Delivering major improvements in dementia care and research by 2015*, Department of Health, London March 2012

4 Alzheimer's Society *Dementia Diagnosis Rates*, Alzheimer's Society website [www.alzheimers.org.uk](http://www.alzheimers.org.uk) Jan 13

5 All Party Parliamentary Group, *Unlocking Diagnosis: The key to improving lives of people with dementia*, July 2012.

6 Alzheimer's Research Trust, *You Gov Poll*, May 2008.

7 Alzheimer's Society, *Alzheimer's Society survey*, September 2008.

8 Alzheimer's Society *Dementia Diagnosis Rates*, Alzheimer's Society website [www.alzheimers.org.uk](http://www.alzheimers.org.uk) Jan 13

experience has shown that presenting to a health professional in primary care does not necessarily have the appropriate outcome. Carers and people with dementia consider primary care, and particularly GPs, as a hindrance rather than a help to a diagnosis of dementia.

Primary care professionals have cited lack of availability of diagnostic tools<sup>9</sup>, the variable quality of and delays in accessing memory services, the lack of post-diagnostic support and treatments as contributory factors to their reluctance to diagnose dementia<sup>10</sup>. In the last few years we have seen a growing evidence base for, and a move towards primary care-based memory assessment services. Such services are not only seen as less stigmatising by patients and carers but are also more efficient and cost-effective. There is better availability of diagnostic tools<sup>11</sup> and more evidence for the benefit of non-pharmacological interventions such as exercise and cognitive stimulation therapy, particularly in the earlier stages of illness<sup>12</sup>.

Through a range of initiatives the Government is encouraging primary care to have a more pro-active attitude towards the recognition of dementia and the care of the elderly. These include the “enhanced services initiative” for the review of people who have conditions that place them at increased risk of dementia, and a named GP for people aged 75 years and over. The reorganisation of the NHS and the emergence of the Clinical Commissioning Groups have placed primary care at the centre of determining the shape of health and social care provision.

Increasingly we are seeing a greater number of GPs with a positive attitude towards earlier diagnosis of dementia. There remain some who question this approach, particularly “a target diagnosis rate” and the potential for over and / or miss-diagnosis of dementia. The improved quality of memory services through initiatives such as the Memory Service National Accreditation Programme (MSNAP), the increased awareness of dementia and those “at risk of dementia” in primary care, the improved availability of support throughout the dementia journey and the expanding body of evidence for the value of non-pharmacological interventions all serve to mitigate concerns about earlier diagnosis of dementia.

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9 Ballard C, Burns A, Corbett A, Livingston G, Rasmussen J. *Helping you to assess cognition: A practical toolkit for clinicians*, 2013. [www.alzheimers.org.uk/cognitiveassessment](http://www.alzheimers.org.uk/cognitiveassessment)

10 All Party Parliamentary Group, *Unlocking Diagnosis: The key to improving lives of people with dementia*, July 2012.

11 Alzheimer's Society, *Alzheimer's Society survey*, September 2008.

12 Ballard C, Burns A, Corbett A, Livingston G, Rasmussen J. *Helping you to assess cognition: A practical toolkit for clinicians*, 2013. [www.alzheimers.org.uk/cognitiveassessment](http://www.alzheimers.org.uk/cognitiveassessment)

As I have said previously “Earlier diagnosis will not alter the ultimate outcome, but the better informed and prepared we all are, the better equipped we will be to tackle the challenges that dementia presents”<sup>13</sup>.

### **Author declaration of interests**

#### **NHS:**

- East Surrey CCG Commissioning Lead for Mental Health, Learning Disability and Dementia
- SCN SE Coast Clinical Lead Dementia
- Co-developer of Dementia Roadmap and MoodHive (Depression Anxiety Pathway)

#### **Royal College of General Practitioners**

- Chair Learning Disability Special Interest Group
- Clinical Champion Dementia

#### **Consultancy / Advisory Boards / Speakers Bureau:**

Autism Therapeutics, AstraZeneca, Alzheimer’s Society, CereStimChronos, Lilly, Napp, Otsuka, Pfizer, Roche, Servier, Targacept

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<sup>13</sup> Rasmussen JGC, *Would doctors routinely asking older patients about their memory improve dementia outcomes? Yes*, BMJ 2013;346:f1780 doi:10.1136/bmj.f1780 Published 26 March 2013

# Empowering people with dementia

**Dianne Gove, PhD and Helga Rohra**

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Stigma is a complex social phenomenon which is the result of a process in which a range of components converge, namely labelling, stereotyping, cognitive separation, loss of status and discrimination, within the context of the exercise of power.<sup>12</sup> It is also an attribute shared by a group of people which is considered as socially salient. The impact of perceived threat or peril has been described as a key factor contributing towards a particular attribute being considered a stigma.<sup>3,4</sup> However, it is the meanings which come to be associated with a particular attribute which result in it being considered a stigma and not the attribute per se.<sup>5</sup>

Since its establishment in 2012, the European Working Group of People with Dementia<sup>6</sup> (EWGPWD) has been challenging the way that dementia is perceived and the stigma of dementia in Europe. There are currently 12 men and women in the group with different types and stages of dementia, aged 56 to 74 and each from a different country. It is not a support group but a working group whose aim is to ensure that the activities, projects and conferences of Alzheimer Europe duly reflect the priorities and views of people with dementia. The chair of the group also sits on the board of Alzheimer Europe.

The EWGPWD challenges the social saliency of terms such as dementia and those related to specific forms of dementia rather than the actual use of such terms. Through their openness and self-labelling, not only as people with dementia but as experts in the experience of dementia,

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1 B.G.Link & J. C. Phelan, Conceptualizing stigma. *Annual Review of Sociology*, 27, 2001, pp. 363-85.

2 B.G.Link & J. C. Phelan, Stigma and its public health implications. *The Lancet*, 367, 2006, pp. 528-9.

3 C. Stangor, & C.S. Crandall, Threat and the social construction of stigma. In T. F. Heatherton, R. E. Kleck, M. R. Hebl, & J. G. Hull, *The Social Psychology of Stigma*, 2003, (pp. 62-87). The Guilford Press.

4 E.E. Jones, A. Farina, A.H. Hastorf, H. Markus, D.T. Miller & R.A. Scott, (1984). *Social stigma: the psychology of marked relationships*. WH Freeman and Company, 1984.

5 Jones et al., 1984.

6For details of the members, see: <http://www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia>

they publicly reject any loss of social status or assumption that dementia reduces them “from a whole and usual person to a tainted, discounted one”.<sup>7</sup>

Their activities, positive approach and more nuanced portrayal of dementia challenge many of the stereotypes that people have of dementia. Members of the EWGPWD describe the emotional, physical and social impact of dementia on their lives and acknowledge their fears but also their desire to get on with life. They shift the focus from deficits to remaining capacities and from a perceived lack of quality of life to the desire to play an active role in society for as long as possible, albeit it with the necessary support.

Contact with people with mental disorders has been associated with a decreased desire for social distance.<sup>8</sup> In addition to speeches, participation in European projects, articles and television and radio interviews, the members of the EWGPWD are keen to promote direct contact with other members of society. They achieve this at European dementia conferences through a stand, networking and interactive workshops. Amongst their aims, they would like to help reduce the fear of dementia and to challenge the way that dementia is perceived and portrayed. In addition to efforts increasingly being made by the mass media to show the different faces of dementia, the EWGPWD is promoting a new way of addressing and communicating about dementia within society. Direct contact may lead people to question the images and beliefs they have about dementia and the tendency to consider people with dementia as a group apart (i.e. as “them” as opposed to “us”). The dissonance that contact creates may lead to improved attitudes towards the individuals concerned which may in turn be extended to other people within the wider stigmatized group.<sup>9</sup>

According to Link and Phelan,<sup>10</sup> there would be no stigmatization without the exercise of power. Although people with dementia are potentially vulnerable due to the symptoms of dementia, with the support of Alzheimer Europe and its national member Associations, the EWGPWD is empowered to make its voice heard directly at the European level. This

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7 E. Goffman, *Stigma: notes on the management of spoiled identity*, Penguin Books, 1963, p. 12.

8 S.M. Couture & D.L. Penn, Interpersonal contact and the stigma of mental illness: A review of the literature. *Journal of Mental Health*, 12, 3, 2003, pp. 291–305.

9 D.M. Desforges, C.G. Lord, S.L. Ramsey, J.A. Mason, M.D. Van Leeuwen, S.C. West, & M.R. Lepper, Effects of structured cooperative contact on changing negative attitudes toward stigmatized social groups. *Journal of Personality and Social Psychology*, 60, 4, 1991, pp. 531–44.

10 Link and Phelan, 2006

presents a picture of people with dementia as citizens with equal rights and legitimate demands for appropriate support rather than as a powerless group. Together with national Alzheimer associations, the members of the EWGPWD provide valuable insight into the experience of dementia in countries where attitudes, practices and support differ considerably, thereby helping ensure that European policy makers do not overlook discriminatory practices and inequities in countries where the voice of people with dementia is perhaps less audible.

The EWGPWD is not representative of all people with dementia but it aims to ensure that people with dementia all over Europe are considered as equally valuable members of society and treated accordingly. The members of the EWGPWD are currently approaching the end of their first term of office. In the last two years, in addition to their formally established goals, they have, through their courage and dedication, contributed towards challenging the stigma of dementia in Europe.

# Chapter 4: Exploring cross cultural and country responses to dementia

## New perspectives and approaches: A multi-faith/cultural view

**Dr Sahdia Parveen, Professor Jan Oyebode and Professor Murna Downs, Bradford Dementia Group, University of Bradford**

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### **Number of people with dementia in Minority Ethnic communities**

Currently the Minority Ethnic (ME) population is significantly younger than the white British population. By 2051, however, 30% of the Black Caribbean and 21% of the British Asian Indian population will be aged 65 years and over. As such, the number of individuals diagnosed with dementia from ME communities will double by 2056. Furthermore, young onset dementia is more common within ME populations (6%) than in the white British population (2%).<sup>1</sup>

### **Cultural explanations for dementia and their influence on dementia as a stigma**

Dementia is a stigma in all cultural groups. What differs between and within cultures is the reason dementia is considered to be a stigma. Many ME communities do not view the symptoms associated with dementia as being due to a progressive brain disease of old age and this can lead to greater stigmatisation in these communities.<sup>2</sup> In most ME communities, while memory loss is not considered to be a health problem nor to carry stigma, when dementia is more advanced or manifested through changes in behaviour its association with mental illness means it is viewed as a stigma. Different ME communities have different explanations for what causes dementia – many of which are associated with significant stigma,

<sup>1</sup> Census, (2011). Office for National statistics; General register office for Scotland. [www.statistics.gov.uk](http://www.statistics.gov.uk)

<sup>2</sup> J. Moriarty, N. Sharif and J. Robinson. *Black and minority ethnic people with dementia and their access to support and services*. Research briefings Retrieved 6th August, 2013 <http://lx.iriss.org.uk/sites/default/files/resources/briefing35.pdf>

not just for the person but also for their family. For example, explanations of dementia include possession by evil spirits (Black Caribbean communities), having an evil spell cast on you (Pakistani communities), and retributions for misdeeds (Indian communities). Such beliefs, while not held by all members of the community, add to stigmatisation as the person with dementia is considered “at fault” and is blamed for their condition. Younger members of South Asian families where someone has dementia may also be affected by courtesy stigma as their marriage prospects may be reduced due to the perception from the community of “bad blood in the family”.

### **Dementia, culture and multiple jeopardy**

Another difference between and within cultures is the additional stigmatising attributes with which the stigma of dementia can combine. When dementia co-occurs with other stigmatised attributes, such as old age and mental health, it can produce multiple jeopardy. Old age itself is devalued in contemporary British society, such that many in mainstream communities face a double jeopardy of being old *and* living with dementia. By contrast, many U.K. ME cultures still hold to the traditional value of “respecting your elders”. Within many ME communities, in contrast, people with dementia will face the stigma of dementia combined with the stigma of their minority ethnic status, *and* being (or being perceived as) migrants, *and* holding lower socio-economic status. In addition, being female *and* old may carry stigma in some cultures. The diagnosis of dementia often adds another layer of stigma leading to feelings of deviancy and shame, delaying help-seeking, and adding to social exclusion.

### **Cultural values and the stigma of care**

Cultural values of filial obligation (a sense of duty to provide care for family members) have been found to be stronger in ME communities, particularly within Asian communities.<sup>3</sup> This sense of duty to provide care often fosters stigma in accessing services. Asian carers of persons with dementia find that they face the additional barrier of the extended family who may perceive the use of services as the carer not fulfilling their duties. The wider family and community may consider the carer to have “abandoned their family member” by using services. Self-blame, for not coping well, has been found to be a common feature within South Asian carers and is related to greater carer burden.

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3 S. Parveen, V. Morrison and C. A. Robinson. *Ethnicity, familism and willingness to care: Important influences on caregiver mood?* *Aging and Mental Health* 17(1), 2013, p.115-124

## Cultural and religious influences on the operation of stigma

The way stigma operates differs across cultural communities and is often linked to groups' historical experiences and religious beliefs.<sup>4</sup> For example, war and persecution have featured within recent Eastern European history, and many had to keep their identity secret to survive. The stigma associated with their identity has led to people keeping their own affairs in the family. This has influenced how the stigma associated with dementia is managed, in that it may be kept "behind closed doors". In contrast, the stigma associated with dementia is rooted in religious identity within South Asian communities. For example, families and persons with dementia face the stigma of being perceived by others of their own religion as bad or evil because they have not been strong enough in their religious beliefs, and have "not prayed enough" to keep dementia away.

### Consequences of stigma

There is growing evidence that the consequences of the stigma of dementia are more severe for ME communities. Cultural stigmas (along with lack awareness) are considered significant barriers to persons with dementia seeking health service help, being diagnosed in a timely manner and accessing statutory support services.<sup>5</sup> ME communities perceive there to be stigma associated with using memory assessment and support services as such services are often provided under the banner of mental health. Due to the stigma associated with accessing mental health services, there appears to be a preference from ME groups for community-based support. Community-based support groups, which include workers from the cultures they serve, are well positioned to provide culturally sensitive services and to allow service users to build trusting relationships with the support group organisers.

Family carers also perceive that a diagnosis of dementia receives more condemnation/discrimination from members of their own cultural group than the white British culture. It is not only the person living with dementia but families also that may experience social isolation from the extended family and wider community. Thus, greater awareness is vital to reduce consequences of stigma within communities.

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4 J. Mackenzie. *Stigma and Dementia: East European and South Asian family carers negotiating stigma in the UK*. *Dementia* 5(2), 2006, p.233-247

5 N. Mukadam, C. Cooper, B. Behzad and G. Livingston. *Why do ethnic elders present later to UK dementia services? A qualitative study*. *International Psychogeriatrics* 23(7), 2011, p.1070-1077.

## **Intra cultural differences**

While it is tempting to think in simplistic terms about certain ethnic groups having certain understandings and conceptualisations of dementia, there is considerable variation within ethnic groups. These differences can be attributed to different social and structural factors including degree of acculturation, education, household composition and neighbourhood structure, literacy including health literacy, age, gender, and, as discussed above, concepts of filial obligation.<sup>6</sup>

## **The potential of dementia-friendly community initiatives**

Reducing the stigma associated with dementia is a key policy priority, with an increasing number of cities implementing the “dementia-friendly community” model. Approaches used within ME communities can be tailored to address their specific cultural needs. Successful approaches will be rooted within local and cultural contexts, designed by local stakeholders. Dementia-friendly communities, with their imperative for collaborating with individuals from local communities when developing approaches to reduce dementia-related stigma, hold great promise.

It is vital that ME communities are not considered as qualitatively “different” or “apart” from the majority cultural group in the UK as this lends to further stigma that ME communities have to manage. Stigma can only be reduced if inclusion is applied to all individuals irrespective of their ethnic background, culture, religion and whether they have dementia.

## **Conclusion**

The stigma attached to being of an ME group and living with dementia is fluid and dynamic. With the many initiatives being developed across the UK, the awareness and understanding of dementia across all cultural groups will no doubt be changing. In Bradford, as elsewhere in the country, ME communities are now taking the first steps to openly discuss and acknowledge dementia in a positive way. This gives hope for the future.

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<sup>6</sup> L Boise. *Ethnicity and the experience of dementia*. In M Downs and B Bowers (Eds) *Excellence in dementia care: research into practice*, 2008, Maidenhead: Open University Press.

# Stigma as a barrier to finding solutions for dementia

## Marc Wortmann

*Marc Wortmann is Executive Director of Alzheimer's Disease International (ADI). Marc studied Law and Art in the city of Utrecht in the Netherlands and was a member of the Parliament of the Province of Utrecht and worked closely with various charities and voluntary organisations. He became Executive Director of Alzheimer Nederland in 2000. Marc joined ADI by the end of 2006 and is responsible for external contacts, public policy and fundraising. He is a speaker at multiple events and conferences on these topics and has published a number of articles and papers on dementia awareness and public policy.*

Dementia is a worldwide problem. Although it is often perceived as a disease of the most developed part of the world, the majority of people with dementia actually live in lower and middle-income countries (LMIC). According to our most recent data, there are 44 million people with dementia worldwide of whom almost 28 million (62%) live in LMIC<sup>1</sup>. Low levels of understanding about dementia lead to various misconceptions in many parts of the world, resulting in perpetuation of stigma which is prevalent in most countries at various levels. People with dementia are often isolated, hidden or even frightened, because of stigma or the possibility of negative reactions from neighbours and relatives to behavioural and psychological symptoms.

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) produced its key annual World Alzheimer report on stigma in September 2012.

In the survey done for this report, many people with dementia and their family carers have answered a number of questions about the stigma around Alzheimer's and other dementias. From this report, it appears that 75 percent of the participants thought that there was a stigma around people with Alzheimer's disease. Someone from the USA said: "People barely dare talk about it. I have survived the disease, cancer. At that time, people constantly asked how I was doing. Now that I have got

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<sup>1</sup> The Global Impact of Dementia 2013-2050, Policy Brief for Heads of Government, Alzheimer's Disease International, December 2013; <http://www.alz.co.uk/research/G8-policy-brief>

Alzheimer's disease, nobody asks." Many people acknowledged that friends excuse themselves. Children also stop visiting their parents. They think the syndrome of their father or mother is too hard to watch. And a family carer from Venezuela said: "We have to make everybody conscious about dementia and explain what it is, from the first phase onwards, so that respect and support for this disease becomes a part of our culture."<sup>2</sup>

A very shocking story came to us from Namibia, where members of the recently formed Alzheimer association released a woman who was chained and kept in a hut for 20 years because she had dementia. Several other African associations confirmed that similar things still happen in their countries as well.

The World Alzheimer Report 2012 reveals stigma and social exclusion are major barriers for people with dementia and their family carers. Nearly one in four people with dementia (24%) hide or conceal their diagnosis citing stigma as the main reason. Furthermore, 40% of people with dementia report not being included in everyday life. The report reveals that people with dementia and carers feel marginalised by society, sometimes by their own friends and family members. What they want is to be treated like normal people with a focus on their abilities and not on their impairments.

The Alzheimer's and dementia movement might have contributed as well to stigma, without having this intention. By framing the disease as an 'epidemic' or a 'thief' that steals your personality, it has contributed to more awareness but on the other hand raised the fear of dementia as well. From my own experience, I know that this has been an ongoing concern. In the last 10-15 years, people with dementia themselves have spoken out and become more part of the movement. As a result, the language has changed and more emphasis has been put on living well with dementia and how our communities can respond to this.

How can we overcome stigma? The ADI report gives ten recommendations (see below). Proper information, openness about the disease and initiatives to make communities more dementia-friendly can create a society in which people with dementia are accepted as part of the community. I am convinced that this 'normalisation' of dementia is a key factor for the development of better care and support, for investments to improve the prevention and treatment of Alzheimer's disease and other dementias, and hopefully, one day finding a cure.

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<sup>2</sup> World Alzheimer Report 2012, Overcoming the stigma of dementia, London, September 2012; <http://www.alz.co.uk/research/world-report-2012>

## Recommendations to overcome 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

# A UK policy perspective on dementia and stigma

## Jon Rouse

*Jon Rouse was appointed Director General, Social Care, Local Government and Care Partnerships in March 2013. Before joining the department, he was Chief Executive of the London Borough of Croydon. Other previous roles include Chief Executive of the Housing Corporation and Chief Executive of the Commission for Architecture and the Built Environment. He has also held a wide range of non-executive positions with organisations including English Partnerships and Homelessness International, and was a non-executive director on the Department of Health's board until 2010.*

Can you imagine what it is like to live with dementia? Imagine feeling confused, frightened, frustrated, unable to recognise people around you, and struggling to do everyday tasks. Now imagine feeling isolated and stigmatised in your own community – imagine that people you know well are crossing the street to avoid you – and this compounds how you are feeling. Whilst this is not the experience of everyone with dementia, and let's not forget that many people live well in a caring and supportive community, it's certainly the experience that some people have. An Alzheimer's Society survey<sup>1</sup> showed that over 60% of people with dementia felt anxious or depressed, a third said they had lost friends, and of those living alone, over 60% of people with dementia reported feeling lonely.

Since joining the Department of Health a year ago, I have spent a large proportion of my working life exposed to the issue of dementia, and consequently I spend a lot of time thinking about it. But that should come as no surprise given the estimated 800,000 people in the UK with dementia and the 550,000 family members who care for them. Dementia is a priority for me, for Jeremy Hunt and, importantly, for David Cameron who, in 2012, launched his Challenge on Dementia. The Challenge is not just about improving health and care and research, it is also about creating dementia-friendly communities that understand how to help people with dementia and their carers.

Dementia isn't just a challenge for the UK, it's a challenge for the world. Around the world, someone develops dementia every four seconds. Over

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<sup>1</sup> <http://www.alzheimers.org.uk/dementia2013>

35 million people have it, and as people live longer than ever before, this is set to double every twenty years. Among them, 62% live in low- and middle-income countries, and this proportion is projected to rise to 71% by 2050.

The G8 Summit we hosted last December showed that the UK can provide global leadership and bring other countries together. We pledged to increase the amount spent on dementia research and to identify a cure, or a disease-modifying therapy, for dementia by 2025.

Attitudes to dementia are changing. As a society, we used to think it was an inevitable part of ageing but we now know it's a group of diseases that can happen to anyone. We used to think that there was nothing that could be done to prevent dementia, but we know now that good cardio-vascular health can help prevent vascular dementia.

Awareness of dementia has increased dramatically over the last years. There are stories in newspapers every few days and frequent features on television. Many public figures and celebrities have come forward to talk openly, and movingly, about the impact that dementia has had on them and their loved ones. In some communities, awareness of dementia is limited, there is no word for dementia in some languages and a lack of recognition of dementia as a condition for which help is available.

Awareness is one thing, but it could just mean that people have now heard of dementia. What we need is to increase understanding, as this will help to reduce the stigma attached to the condition and help people with dementia and their carers to feel part of their community and live as well as they can with dementia. The stigma attached to dementia also means that people with it can be unwilling to seek help and get a diagnosis. Without a diagnosis, they are unable to access the support they and their families need to live well with the condition.

The Dementia Friends initiative is helping people to understand what it's like to live with dementia. It's not about becoming an expert in dementia, but instead learning what it's like to live with the condition and what can be done to help.

As dementia develops, people sometimes need a helping hand to go about their daily lives and feel included in their local community. Becoming a Dementia Friend is not about becoming an expert. It is about being helped to understand more about what dementia is, how it can affect a person's ability to do everyday things and how to make a difference. We aim to have one million Friends by 2015 and we are already making good

progress towards that, with over 80,000 Friends already signed up and a further 190,000 committed to by businesses.

Hand in hand with Dementia Friends, the dementia-friendly communities programme is striving to make towns and cities more understanding of dementia and better equipped to offer support with the day to day activities that we all take for granted, such as shopping, banking and using public transport.

Dementia is embedded as a Government priority, and we increasingly see it prioritised locally by the NHS, social care, the third sector and private businesses. It's a movement that is growing every day and one which sees a society that better understands dementia and sees it not as something stigmatic but as a condition that can be alleviated and perhaps one day cured.

# Chapter 5: Insights and future actions

## Summary of discussions and feedback from high level discussion in the House of Lords

**Compiled and edited by George Holley-Moore, ILC-UK**

The high-level discussion in the House of Lords produced some insightful and varied viewpoints which helped inform this compendium. Attendees were invited to answer eight questions relating to dementia and stigmatisation; collated summaries of responses to each question are included below.

### **What do you think are the underlying reasons or factors that contribute to the stigmatisation of people with dementia and their carers?**

Many respondent's referenced 'fear' as an underlying reason for stigmatisation. There were varied reasons given for this, such as the fear of losing one's own identity, or a fear of being a burden to others. A common response was that there remained a fear of the 'other' in our society, or the fear of the unknown, contributing to stigmatisation. Some respondents also felt that stigmatisation of dementia was part of a wider stigmatisation of ageing and older people, with society often being told about the 'problem' of an ageing society. Another common response from participants was that media representation of dementia contributes to stigmatisation. One example given of a negative representation was that media representation only included people in the late stages of dementia, usually in care homes – an argument was made that younger onset dementia is severely underrepresented by the media, and in fact many people with dementia live in the community, and are often able and fit.

Other reasons offered for stigmatisation were cultural and societal reasons. For example, dementia can sometimes lead to certain unsocial behaviours that are treated with disgust in our society. One respondent also stated that in our society which values the concepts of individuality and autonomy so highly, stigmatisation can arise from a reduction or cessation of these concepts in a person with dementia.

## **What would be the benefits of scientific research aimed at understanding the neurobiological causes of the stigma of dementia?**

There were many positive responses welcoming the idea of neurobiological research. Many respondents felt that if it led to an increased understanding of the underlying causes of stigma, then research into this area is important. For example, if an appreciation of the biological basis of stigmatisation is central to tackling its expression, then people could address negative feelings with greater understanding. Some attendees responded positively to the idea of more scientific research on the neurobiological causes of stigmatisation and dementia as they believed that it could result in quicker diagnosis, as well as possibly encouraging evidence based education campaigns to alter the image and reaction to dementia and combat the 'disgust' that still often surrounds the condition.

There were other respondents who felt that research of this nature would not be the best use of what is already limited funding for dementia research. Some had concerns that funding would be of better use going into outcomes such as prevention, potential causes, early intervention, post diagnostic support, treatment and care. Some respondents voiced other concerns about how effective research into this area would be; for example it was suggested that whilst the research might be interesting and informative, it might not necessarily reveal a method of tackling the stigma.

## **What do you feel is the individual and wider impact of such negative and discriminatory attitudes? For example individuals or families not seeking a diagnosis?**

A common response from participants was a fear that negative and discriminatory attitudes towards dementia impacted on diagnosis rates, due to a reluctance to seek help. The importance of early diagnosis was stressed by a number of respondents, with benefits including improved and earlier support for individuals and their families, as well as effective treatment for early symptoms. There were a number of responses which focussed on the impact these attitudes had on people within the health service; for example one opinion was that GP's are reluctant to make a diagnosis due to the belief that nothing can be done.

Respondents most frequently cited social isolation as the outcome of

discriminatory attitudes towards people with dementia. Depression, increased stress and agitation were all named as consequences of this social isolation. Isolation may, one respondent noted, possibly even accelerate the progression of the neurobiology of the disease. The social isolation that is a result of these attitudes can result in the person with dementia no longer being viewed as an individual, and suffer a loss of personhood as a result. It was also stated that negative attitudes towards dementia can lead to family members and carers becoming socially isolated, as stigma surrounding dementia leads to a reluctance to seek support and information that is often needed.

### **What would be the added value to health or social care if we reduced stigma? For example, timely diagnosis leads to greater support and possible delays to residential care.**

There was a feeling that improved diagnosis rates would be a benefit of reducing stigma surrounding dementia. Better rates of diagnosis could improve care in the years of early dementia as well as giving more time for important decisions to be made, such as those surrounding end of life choices. Others thought that the quality of professional support would also increase, and improvements would not just be found in the obvious settings of hospitals and care homes, but reduced stigma would result in a better environment for people with dementia in places such as dentists and opticians. Some respondents noted the added value would be that reduced stigma would encourage high-quality people in the health and social care sector to focus on dementia, although further steps such as increased pay and training were also needed.

Some respondents felt that a reduction of stigma would lead to further research and funding into alternative models of care which would support independent living for people living with dementia, such as dementia supportive communities. Whilst there was a view that reduced admission to residential care would be an outcome of reduced stigma, it was stated by others that residential care would improve and become more attractive to people with dementia and their families, with greater support offered and less incidences of abuse.

### **What can we learn from other groups that are or have been historically discriminated against; for example people with disabilities with regard to stigma?**

Respondents largely felt that there are lessons to be learned from groups

that have been historically discriminated against. A common suggestion was to increase the visibility of the marginalized group, such as through participations in demonstrations or protests, or the use of celebrity spokespeople; for example one respondent suggested celebrities and politicians could 'come out' as having a relative with dementia. Visual integration and identification was also given as something to be learned from other discriminated groups, for example the use of pink ribbons for breast cancer and red ribbons for AIDS.

A concerted effort to normalise and mainstream individuals that have been historically discriminated against was suggested as a lesson that can be learned; one respondents gave the example of people with learning difficulties in the past being kept in institutions. One respondent thought that a large part of the process of reducing stigma should be society realising dementia can and will affect many of us, thereby galvanising a process of normalisation.

### **Do we have enough evidence to fully understand the motivations, nature and current impact of stigma on dementia?**

Most respondents did not think there was enough evidence to fully understand stigma of dementia. There were however varied opinions as to which direction additional research should take. Suggested areas of further research included the factors that govern the stigma response, how to overcome the stigma, why there is a wide variation in diagnosis rates across the country and also the best methods of education and training of health care professionals and families of people with dementia. One respondent felt that whilst we currently do not have enough evidence, in the meantime that should not prevent attempts to reduce stigma for people with dementia now; whilst it often takes a long time to extrapolate out the knowledge from research collected, action must be taken now to prepare for the ageing baby boomer generation.

There were other respondents who disagreed, and thought that there was little need for further research. Some felt that in fact there was already enough research on stigmatisation and dementia to start taking action, stating that the evidence indicates stigma increases isolation and late diagnosis. Others felt that whilst there might not be a large amount of research conducted on dementia and stigma, enough had been undertaken on similar topics, such as discrimination against mental illness to develop a plan. There was also a feeling amongst other respondents

that change can be learned without further research, by learning from the campaigns of other discriminated against issues, such as HIV/AIDS, cancer and learning difficulties.

### **What should happen next and by whom?**

A wide range of views were expressed by respondents when asked 'what should happen next?'. A number of people thought that further research on dementia was needed. It was common for respondents to note that in order for more research to be conducted, there needs to be an increase in funding. Further research, one respondent stated, is needed as the most effective way to reduce fear and prevent stigmatisation is to develop treatments for dementia. One opinion was that work should be done on stigma across mental disorders, to collate knowledge and understand the neurobiology of stigma.

Other respondents called for a political commitment to tackle stigmatisation and dementia, with a policy focus on improving equality of service provision, training of professionals and communicating what responsible citizens should do to care for their neighbors, family or friends with dementia. As well as increased political commitment, some respondents advocated reforming care home environments, with suggestions to tackle poor management, encouraging empathy amongst staff members and increased training and education of care home employees. There were further suggestions as to what should happen next, such as educating the public to promote an understanding of dementia, creating more dementia friendly places and services, and increasing the financial resources for carers.

### **What, if any, public awareness campaigns, educational programmes do you feel would be most effective in tackling this issue?**

The general consensus was that educational programmes and public awareness campaigns would be a good thing. The need for people with dementia to be more visible and less institutional or home based was expressed; this could be achieved through dementia-friendly communities. Public awareness campaigns could also promote early recognition and diagnosis of dementia, which, it was suggested, would reduce stigmatisation. One respondent stressed the need for any public awareness campaign to be on-going, not just a 'flash in the pan'. The use of media, especially TV and social media, was a common suggestion from respondents. Suggestions included involving more people with dementia

who are living in the public eye in media campaigns, more of a supportive and empathetic portrayal of dementia in the media, and ensuring that journalists have a greater awareness of the issues surrounding dementia.

Putting an emphasis on 'positive living' was also suggested by respondents; for example seeing and hearing from people with early onset dementia living in the community leading positive lives. It was also common for respondents to suggest public education efforts aimed at young people. These included identifying younger people whose lives have been affected by dementia who can champion the issue, and more work in schools to increase awareness.

# Where are we going? The dementia research agenda

## Medical Research Council, Alzheimer's Research UK and Alzheimer's Society

It has been encouraging to see significant increases in investment in dementia research over the past few years, and as funders of research we have been central to that increased investment. We are all working to further the post-G8 Dementia Summit agenda, to increase the impact of research into the dementias and address the growing global burden of neurodegenerative disease. This is an exciting time for dementia research, with many new and energising initiatives and together we are steadily increasing the research potential in the dementia field. However, there has been no significant and joined-up focus on stigma from a research perspective.

This debate provided a unique opportunity to focus on a little-researched area that has a major impact within society. Talking openly about dementia is an important step of the process. We wanted to highlight what may not be widely realised - that stigma exists and that the evidence shows that it is likely to worsen a person's symptoms and quality of life through loneliness and rejection. Stigma affects people's perceptions, which means that people with dementia may not be treated as effectively as other older recipients of health care.

Through the debate and this compendium report we seek to raise awareness of this complex issue in a way that complements policy work by other agencies and organisations and - importantly - we also want to begin a broader discussion about whether stigma could be a new area for neurosciences research.

We strongly support the need for solidarity and behavioural change within society. As recommended in the 2009 Nuffield Council on Bioethics report, this can only be achieved through more education, ensuring that people who deliver services work together and treat people with dementia with respect. We encourage anyone with early signs of the condition to overcome their fear or misgivings and benefit from available support at the earliest opportunity. Timely diagnosis is also crucial because we want people to receive maximum benefit from any new therapeutic approaches that are developed from current and future research efforts, which are likely to be most effective the earlier they are given.

The high level discussion in the House of Lords lacked consensus on whether there are specific biomedical research questions to be addressed. The debate reflected a wide range of perspectives. Some consider that most of the issues stem from psychological factors. Others think that we don't need further understanding, we simply need proactively to eliminate stigma through awareness and behaviour change, to identify when stigma occurs and take action to prevent it from happening. It was also suggested that we could learn from other disease areas, such as cancer, where stigma has been largely eradicated. However, views were divided and we also heard that a better understanding of the biology could allow us to target specific strategies and interventions to challenge stigma.

In the UK, we are fortunate to have a range of funding agencies that span all aspects of dementias research from discovery science through to health and social care research. The funders of this report challenge researchers to respond creatively to the questions set out in this report. through the variety of funding mechanisms, to establish whether there are indeed new scientific findings to uncover.

## Annex I: Attendees at private dinner in the House of Lords

First Name	Last Name	Position	Organisation
Debbie	Abrahams MP	Member of Parliament for Oldham East and Saddleworth	Parliamentarian
Adrian	Alsop	Director	ESRC
Professor June	Andrews	Director	Dementia Services Development Centre, University of Stirling
Sir Tony	Baldry MP	Member of APPG on Dementia	Parliamentarian
Nicole	Batsch	PhD student	KCL
Cathy	Bird		Alzheimer's Society Research Network
Hazel	Blears MP	Member of APPG on Dementia	Parliamentarian
David	Blunkett MP	Member of APPG on Dementia	Parliamentarian
Professor Dawn	Brooker	Director	Association of Dementia Studies, University of Worcester
Dr Doug	Brown	Director of Research and Development	Alzheimer's Society
Dr Rob	Buckle	Head of Theme for Dementias	Medical Research Council
Michael	Connor	Partner to Lesley Finlay	
Andrew	Cornwall		Alzheimer's Society
Professor Phil	Cowen	Professor of Psychopharmacology	University of Oxford

Shirley	Cramer CBE	Chief Executive	Royal Society for Public Health
Professor Murna	Downs	Head of Bradford Dementia Group	Dementia Group University of Bradford
Anna Lesley	Eden Finlay	Manager	Young Dementia UK
George	Freeman MP	Member of Parliament for Mid-Norfolk	Parliamentarian
Penny	Garner	Founder & Clinical Director	Contented Dementia Trust
Vicki	Graham	Champion	Alzheimer's Research UK
Professor Kim	Graham		Cardiff University
Dr Nori	Graham		Royal College of Psychiatrists
Richard	Graham MP	Member of APPG on Dementia	Parliamentarian
Baroness Sally	Greengross		ILC-UK
Dr Neil	Harrison	Reader in Neuropsychiatry	Brighton and Sussex Medical School
Hilda	Hayo	Director	Dementia UK
Susie	Hewer	Champion	Alzheimer's Research UK
Baroness	Hollins	Member of APPG on Mental Health	Parliamentarian
Professor Clive	Holmes	Professor of Biological Psychiatry	Southampton University
Jeremy	Hughes	CEO	Alzheimer's Society
Dr Julian	Hughes	Institute for Ageing and Health	Newcastle University
Lorraine	Jackson		Department of Health
Piers	Kotting		Dendron
Dr Heidi	Larson		Partner to Peter Piot
Professor Gill	Livingston	Professor of Psychiatry of Older People	University College, London

Professor Seth	Love	Director	MRC Brain Banks network
Dr Christina	Maciejewski	Co-Director	Dementia Services Development Centre, University of Bangor
Professor Hugh	Markus	Head of Stroke and Dementia Research Centre	Dementia Research Group, St. George's, University of London
Tulip	Mazumdar	Global Health Reporter	BBC
Professor Marion	McMurdo	Chair, Age and Ageing Specialty Group	NIHR
George	McNamara		Alzheimer's Society
Professor Jonathan	Montgomery	Chair	Nuffield Council
Dr Catherine	Moody	Programme Manager	MRC
James	Morris MP	Member of APPG on Mental Health	Parliamentarian
Matthew	Norton		Alzheimer's Research UK
Baroness	O'Neill		Parliamentarian
Professor Carmine	Pariante	Psychological Medicine	King's College, London
Neil	Parish MP	Member of APPG on Dementia	Parliamentarian
Professor Bronwyn	Parry		KCL
Professor Jill	Peay	Professor of Law	LSE
Professor V Hugh	Perry	Professor of Experimental Neuropathology	MRC/University of Southampton
Professor Peter	Piot	Director and Professor of Global Health	LSHTM
Dr Jill	Rasmussen	Clinical Champion for Dementia	RCGP

David	Read	Supporter	Alzheimer's Research UK
Simon	Ridley		Alzheimer's Research UK
Professor Louise	Robinson	Primary Care Professor	University of Newcastle
Professor James	Rowe		University of Cambridge
Professor Barbara	Sahakian	Professor	Neuroscience, University of Cambridge
Jonathan	Scrutton		ILC-UK
Noreen	Siba	Managing Director	ILC-UK
Dr Graham	Stokes		BUPA
Professor Irene	Tracey	Director of Oxford Centre for Functional Magnetic Resonance Imaging of the Brain Centre	The Oxford Centre for Neuroethics
Lord	Turnberg		Parliamentarian
Jessica	Watson		ILC-UK
Dr John	Williams		Wellcome Trust
Rebecca	Wood	CEO	Alzheimer's Research UK
Professor Bob	Woods	Co-Director, Dementia Services Development Centre	University of Bangor
Marc	Wortmann		Alzheimer's Disease International
Cecilia	Yardley	Senior Partnerships Officer (Dementia Programme)	Parkinson's UK

## **Annex II: About the organisations involved**

As noted earlier, this project has involved a variety of partners, please find below further details on some of the organisations involved.

### **The International Longevity Centre-UK**

The International Longevity Centre-UK is the leading think tank on longevity and demographic change. It is an independent, non-partisan think tank dedicated to addressing issues of longevity, ageing and population change. We develop ideas, undertake research and create a forum for debate.

We have worked on a number of projects on dementia, all with the ultimate aim of improving the lives of people with dementia. Work in this area has included: Holding an expert seminar on dementia research and diagnosis, treatment and care in the House of Lords in advance of the DH/MRC Ministerial Research Summit, an expert seminar in the European Parliament on dementia research and working with the Department of Health on producing the report from the Summit.

We have also explored the economic, social and human cost of dementia in a series of events, in London and in Scotland. The ILC-UK has also worked with the Department of Health on the difficult issue of older people with dementia and their rights in terms of relationships and sexual relations. This year, we also produced a report on dementia and prevention with Improving Care exploring potential savings to the state if we were able to intervene successfully on the risk factors that cause dementia—these include physical activity, smoking, obesity and depression. We estimated that over a 27 year period (2013-2040) this could prevent nearly 3 million people developing dementia in the UK – and would reduce the costs to the state in the UK by £42.9 billion between now and 2040 (minus any associated costs of intervention).

### **The Medical Research Council**

The MRC supports and advances medical research in three main ways: through our own research facilities, by funding research centres in partnership with universities, and by providing research grants and career awards to scientists in UK universities and hospitals. MRC funding comes from government but the MRC is independent in its choice of which research to support. The heart of the MRC mission is to

improve human health through world-class medical research. To achieve this, MRC supports research across the biomedical spectrum, from fundamental laboratory-based science to clinical trials, and in all major disease areas. The MRC works closely with the NHS and the UK Health Departments to deliver its mission, and gives a high priority to research that is likely to make a real difference to clinical practice and the health of the population.

The MRC is fully committed to the dementias as a research priority and will meet the Prime Minister's Challenge by doubling funding for dementia research by 2014/15 from £16.9m in 2010/11 to £33.8m by 2014/15. A recent significant investment is the Dementias Platform UK, a multi-million pound (£53m) industry-partnered programme, developed and led by the MRC to accelerate progress in and open up dementias research. Using existing UK population studies, it will transform the way researchers study dementia by providing an unprecedented amount of information on peoples' lifestyles and health records, as well as data from the lab, to really get to the bottom of how and why dementia develops.

## **Alzheimer's Research UK**

Alzheimer's Research UK is Europe's leading charitable funder of scientific research into Alzheimer's and other dementias. Since 1992, we have committed over £53m to over 430 world-class dementia research projects at leading universities across the UK. We fund biomedical research to understand the causes of dementia, improve diagnosis, and to develop effective treatments and preventions. In addition, we help people to understand dementia and the progress being made through research, and forge partnerships with government and other key organisations to make dementia research a national and global priority. Our Defeat Dementia campaign - launched in 2014 - will raise over £100m in five years and outlines our commitment to improving the lives of people with dementia. The campaign will invest in people and partnerships that will grow the research field, including funding a Research Network of over 700 scientists at 15 centres of excellence across the UK. It will support innovative ideas through a range of different research grant schemes and strategic initiatives to ensure the translation of promising research findings towards the clinic. The latter include such as the (£2m) Alzheimer's Research UK Stem Cell Research Centre in Cambridge, a (£30m) network of Drug Discovery Institutes, a (£3m) Dementia Consortium partnering academic researchers across the world with drug

discovery experts, and a (£20m) Global Clinical Development Fund to support clinical trials of potential new dementia treatments. The Defeat Dementia Campaign will also include a £2m prevention initiative.

## **Alzheimer's Society**

The mission of the Alzheimer's Society is to reduce the impact of dementia on lives today and create a world without dementia tomorrow. The Society does this by providing expert care, support and information, campaigning for change and by funding vital dementia research. Alzheimer's Society's research programme 'Care for today and cure for tomorrow' supports research into all types of dementia that aims to drive forward advances in dementia care and accelerate progress towards a cure. Since 1999 the Society has spent almost £30 million on cutting edge research projects investigating the cause, cure, care and prevention of dementia. From 2014 the Society is increasing that commitment even further by spending at least £100 million on new research projects over the next decade.

Alzheimer's Society is building a vibrant UK dementia research community by supporting scientists, clinicians and health professionals to develop their research careers through the Dementia Research Leaders programme. In addition, the Society is accelerating the search for new dementia treatments through their Drug Discovery programme and providing researchers with high quality brain tissue to underpin their work through the Brains for Dementia Research project. Alzheimer's Society's research programme is an active partnership between the research community and people with dementia and their carers. As a pioneer in public and patient involvement in dementia research, the Society's network of over 250 volunteers help the Society decide which research to fund, monitor the progress of research and disseminate its findings to a wider audience. Alzheimer's Society funds research in the UK but works globally on international initiatives to extend the reach and impact of their work.

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Published in October 2014 © ILC-UK 2014

Registered Charity Number: 1080496.

