

# Chapter 16

## Ageism and Dementia



Simon Chester Evans

### 16.1 Dementia and Its Prevalence As a Function of Age

The term ‘dementia’ covers a range of neurological diseases whose most common symptoms include memory loss, disorientation, behavioural changes and difficulties with thinking or problem solving. Dementias are progressive, which means that the structure and chemistry of the brain become increasingly damaged over time. Alzheimer’s Disease (AD) accounts for approximately 60% of dementias but there are many other types including Vascular dementia, dementia with Lewy bodies and Fronto-temporal dementia. Each of these has different neurological characteristics and causes specific symptoms, but it is important to recognise that the experience of dementia, whatever the type, is unique for each individual person.

The number of people affected by dementia worldwide is predicted to rise from 47 million in 2015 to 75 million by 2030 and 130 million by 2050. This situation has led to calls for dementia to be recognised as a global public health priority from the EU (European Parliament 2010), the World Health Organisation (2015) and many individual countries.

Although dementia is not an unavoidable consequence of ageing, and the phenomenon of early-onset dementia is widely recognised, increasing age is undoubtedly the biggest risk factor. For example, the number of people who develop AD before the age of 65 only represents 5% of all those with the disease. The prevalence of dementia increases exponentially with age in all parts of the world. Prevalence doubles with every 5.5 years of age in North America, 6.5 years in West and Central Europe, 6.6 years in South Asia, and 10.6 years in Southeast Asia (Prince et al. 2015).

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S. C. Evans (✉)

Association for Dementia Studies, University of Worcester, Worcester, UK  
e-mail: [simon.evans@worc.ac.uk](mailto:simon.evans@worc.ac.uk)

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So, while dementia is not an inevitable part of ageing, the chances of getting dementia increase incrementally with age. As a result, people with dementia are likely to experience the stigma that is specifically associated with the disease as well as the broader stigma of ageism. This has been called the ‘double stigma of dementia’ (Urbańska et al. 2015).

## 16.2 The Impact of Dementia-Related Stigma

Goffman first used the term ‘stigma’ in social sciences (Goffman 2005), describing it as the relationship between a particular trait and social stereotypes. Link and Phelan (2001) characterised stigma as a multistage process based on labelling, stereotyping, alienation, loss of social status, discrimination and emotional reactions. At an individual level, stigma has been associated with low self-esteem, feelings of shame, a sense of dehumanisation and experiences of social isolation (Urbańska et al. 2015).

There is currently no cure for dementia and the evidence for the effectiveness of treatments that aim to ameliorate the symptoms is not strong. This, combined with growing awareness of the disease and its effects, such as ailing memory, has led to considerable fears of getting dementia (Corner and Bond 2004). One effect of such fears is that a high level of stigma has become attached to dementia, as witnessed by the growing voice of those living with the disease. Because age is the major risk factor in developing a dementia, those with the condition often experience the effects of dementia stigma in addition to ageist discrimination and the distinction between the two types of stigma often becomes blurred. There is substantial evidence that stigma exists towards dementia worldwide (Moniz-Cook and Manthorpe 2009; Prince et al. 2011). Cultural factors can be important. For example, some Asian traditional spiritual beliefs about the causes of dementia can lead to attempts to conceal it within families. There is now a widespread recognition of an urgent need to reduce the stigma and negative connotations associated with Alzheimer’s disease and other dementias more broadly (Batsch and Mittelman 2013; Jolley and Benbow 2000).

A 2014 meta-analysis of 99 research papers (Werner 2014) found substantial evidence of stigma in relation to people living with dementia. The most common negative emotions associated with stigma were shame, humiliation and disgust. Stigma can occur at three levels: self-stigma is the internalisation by individuals of ideas and reactions; public stigma is evident through the reactions of lay persons towards stigmatised individuals or groups; while stigma by association comprises the emotions and beliefs of those surrounding people with dementia, including family members and professionals.

Werner reported that stigma is perceived as pervasive and is associated with negative consequences at four levels. At the individual level it can lead to low self-esteem, feelings of shame and humiliation, and social isolation. For families, stigma can also cause increased burden, depression, concealment, decreased use of services

and feelings of moral failure. At the professional level it can lead to differential or delayed diagnosis or treatment, while the effects of stigma at the societal level include differential access and use of services and increased institutionalisation.

Anger and fear were found to be the primary emotions contributing to stigmatic behaviours in relation to mental illness, while for Alzheimer's Disease it was feelings of rejection including ridicule, shame and impatience. Lower levels of stigma were associated with AD than other dementias. This review found limited use of operational or conceptual definitions or theoretical background when considering stigma and dementia. Where theories were included they were predominantly modified labelling theory (stigma as a social construct reflecting power relations at a society level) and attribution theory (stigma as a process in which cognitive attributions (stereotypes) are followed by emotional responses (prejudices) and behaviour reactions (discrimination)).

It is also important to consider the impact of stigma on the families of people with dementia, who often provide much of the high levels of care and support that are required. This role is crucial to maximising quality of life for people with dementia and delaying moves to institutional care (Brodaty and Donkin 2009). While there are many positive aspects attached to family caring, it can also bring challenges including increased stress, social isolation and economic burden. In the UK there are 670,000 carers of people with dementia, whose caregiving saves the economy an estimated £11 billion a year.

Providing effective support for carers, including psycho-social interventions, is therefore essential to maintaining quality of life for the person with dementia, but good quality support is not always available when required (Manthorpe et al. 2004). When combined with stereotypes that are associated with ageing more generally across a broad age spectrum from fourth grade school children (Seefeldt 1984) to older adults (Dobbs et al. 2008), this kind of 'stigma by association' can lead to both people with dementia and their family carers experiencing double discrimination. This means that they are likely to be discriminated against as a result of having dementia in addition to the wider discrimination that often occurs against people due to their age.

### 16.3 Media Portrayals of Dementia

In many countries across the world dementia has been recognised as a 'crisis', resulting in a surge in policies and strategies aimed not only at finding a cure but also at helping people to 'live well with dementia' (Department of Health 2009), partly by improving the responses of individuals, organisations and professionals. Public awareness has been identified as a key factor, with the media having a central role in creating and reflecting attitudes and opinions. A UK study (Peel 2014) that drew on 350 national newspaper articles and interviews with family carers found that dementia was frequently portrayed as catastrophic. 'Tsunami', 'a bomb ready to explode', 'Alzheimer's epidemic' 'brain-wasting', 'terrible affliction' and

‘worse than death’ are just a few of the newspaper headlines that are quoted. Reporting of this sort can lead to people with dementia experiencing discrimination because of their condition as well as their age.

There are many similarities between the language that was used in the 1980’s in relation to HIV/Aids, despite the fact that dementia is neither contagious nor preventable in any straightforward way. Many of the same terms and assumptions are applied to describe ageing in general, which associates ageing with a range of negative experiences and attributes such as dementia. The author contrasted this to other media discourses around more ‘controllable’ and treatable chronic conditions. For example, people with cancer tend to be portrayed in a more positive way and are often said to be ‘fighting’ the disease. The limited presence of people living with dementia themselves in media coverage was also noted, with a much greater focus on the views of representatives from medical and charitable organisations.

Language is an important element in how health related conditions are represented in the media and more generally, as increasingly acknowledged:

A casual misuse of words or the use of words with negative connotations when talking about dementia in everyday conversations can have a profound impact on the person with dementia as well as on their family and friends. It can also influence how others think about dementia and increase the likelihood of a person with dementia experiencing stigma or discrimination. (Alzheimer’s Australia)

## 16.4 Dementia and Health and Social Care Services

For many people, health and social care services are the main source of information and support for their dementia. However, rates of diagnosis vary considerably across Europe. Most countries report missing 40–60% of expected dementia diagnoses and that when a diagnosis is made, the dementia is often already at a moderate or late stage. Rates of diagnosis vary considerably across the world. For example, one study suggests that 90% of people with dementia remain unidentified in India, while in England the diagnosis rate is 38% and rising. A European study (Brooker et al. 2014) found that while most countries reported missing 40%–60% of expected dementia diagnoses, some countries reported missing above 60%, and some reported missing only 30%. Most also reported that when a diagnosis is made, the dementia is already at a moderate or late stage. A diagnosis of dementia is often a key criterion for accessing the services that statutory health services offer, which makes the generally low rates of diagnosis a major challenge for many people living with dementia.

The findings from Alzheimer Cooperative Valuation in Europe (ALCOVE), a Joint Action co-financed by the European Commission, suggest that few family doctors have adequate training in recognising symptoms of early dementia which, combined with insufficient understanding or clarity regarding their role, can result in low rates of timely diagnoses (Brooker et al. 2014).

A growing body of evidence suggests that timely diagnosis and intervention can be important in maintaining quality of life for people living with dementia and their families (Banerjee and Wittenberg 2009; Mittelman et al. 2008). In addition, early intervention can delay cognitive decline, maintain functional abilities and delay admission to institutional care (Waldemar et al. 2007; Banerjee and Wittenberg 2009; Prince et al. 2011), as well as leading to improved outcomes for family members, delayed placement into long-term care and increased carer coping (Mittelman et al. 2006, 2007).

It can be argued that these low rates of diagnosis are at least partly due to the negative images that are associated with dementia as well as to the blurred perception of dementia as being an inevitable consequence of old age (Brooker et al. 2014). Similarly, limited understanding on the part of caregivers and physicians of the difference between memory processes in aging and Alzheimer's Disease can be a barrier to timely diagnosis (Knopman et al. 2000). This provides another example of how those who have dementia, a disease linked to ageing, are likely to experience double discrimination. Stigma can be a major factor in the person's willingness or reluctance to seek diagnosis and subsequently to seek support (Milne 2010; Burgener and Berger 2008). Similarly, the standard of care provided to people with dementia is often lower due to the impact of stigma on the health care profession (Devlin et al. 2007; Benbow and Jolley 2012). A study based on interviews with family doctors in the North of England (Gove et al. 2016) concluded that there is a need to separate personal fears from professional judgements, and called for training and support in addressing patient fears and exploring early symptoms.

Even when a diagnosis is received, the ALCOVE study suggests that the provision of support is sparse, with 61% of respondents saying that they always' or 'often' provided information about dementia following diagnosis, and 39% providing education and social support. There is also evidence that some treatments that would benefit people with dementia are not offered because of a belief on behalf of some healthcare professionals that rehabilitation is not possible for people living with dementia, despite evidence to the contrary (Evans 2008).

People with dementia are also likely to have a high prevalence of other comorbid medical conditions, many of which are undiagnosed and preventable, for which they are less likely to receive the same treatment than people without dementia (Scrutton and Brancati 2016). Research suggests that 61% of people with Alzheimer's disease have three or more comorbid diagnoses, while the rate of comorbid conditions increases with the severity of the dementia (Fillit 2000; Murali Doraiswamy et al. 2002). This can lead to a range of discrepancies in health outcomes for people with dementia including faster deterioration in daily functioning, a reduced quality of life, and earlier death. For example, UK hospital patients with dementia are over three times more likely to die during their first admission for an acute medical condition than those without dementia. Similarly, urinary tract infections are one of the principal cause of hospital admission for people with dementia (Sampson et al. 2009), despite both conditions being avoidable and relatively easy to manage if treated promptly. More than 50% of patients in America with moderately severe dementia who are admitted to hospital with hip fracture died within

6 months, a much higher rate than for patients without dementia (Morrison and Siu 2000). An Australian study suggested that dementia patients are more likely than those without dementia to develop preventable comorbidities whilst in acute hospital (Bail 2013).

Poor pain management is another common feature of care for people with dementia, with patients with advanced dementia and a hip fracture in America being prescribed one-third of the analgesia compared with other patients (Morrison and Siu 2000). This has far reaching implications because it can lead to unnecessary suffering as well as the potential inappropriate use of psychiatric medications, particularly towards the end of life (Sampson 2006). Reasons for these inequalities include care systems that focus on the dementia rather than the needs of the individual, a lack of dementia training among health professionals, poor medication management, and mis-interpretation of atypical symptoms. These deficits mean that many people are receiving poorer services due to having dementia in addition to the broader manifestation of ageism in the healthcare system, which can also lead to reduced access to services. Further information on this can be found in the chapter on ageism and the healthcare system (Wyman et al. 2018; Chap. 13).

## 16.5 Social Contact and Engagement

The value of social interaction and participation in group activities is widely recognised. Enjoying good social relationships with family, friends and neighbours and engaging in a large number of social activities are key elements of quality of life for older people (Bowling 2011). There is also a strong argument that having opportunities for social interaction is a basic human right for every citizen, irrespective of their health condition. In this section, we explore the impact of growing old on levels of social interaction and how this is exacerbated for people who have dementia.

Much of the literature suggests that older adults tend to experience a reduction in the size of their social network in later life, along with a decrease in the frequency of their social contacts (for example, Lang and Hornburg 1998; Okun and Keith 1998). It is often suggested that this is partly due to significant life events, such as reduced mobility and the death of a partner and peers. A meta analysis by Pinquart and Sorenson (2001) concluded that greater social contact is associated with lower levels of loneliness, although other factors such as the emotional quality of contacts are also likely to be influential.

While it is important to note that the experience of loneliness is a subjective matter, so that someone who has little social contact may not feel lonely, while another person might feel lonely despite a very active social life, there is widespread agreement that for many people growing older comes with increased feelings of loneliness. Pinquart and Sorenson (2001) also suggested that between 5% and 15% of those aged over 65 frequently feel lonely, although this is likely to be an underestimate, while for those aged 80 or over the figure is closer to 50%. In addition,

they concluded that loneliness is more widespread in older age groups, largely due to reductions in the frequency of social contact related to the death of peers (including partners), the loss of social roles and physical/sensory limitations. Lower levels of activity and sensory capacity can hinder social contact and are associated with higher levels of loneliness. In the UK, it has been estimated that about 10% of the general population aged over 65 is lonely all or most of the time (Bolton 2012), which equates to over 900,000 older people. Levels of loneliness among ethnic minority elders are generally higher, with 15% reporting that they always or often feel lonely. Institutionalisation can also be associated with increased loneliness, partly because people who move to residential settings tend to be those with fewest family members who also lack informal support systems.

There are several theories concerning why social contact is of such value to individuals, as summarised by Bolton (2012). For example, the ‘stress regulator’ hypothesis suggests that social relationships provide resources that aid adaptation to stressful events, including illness and life transitions, and enable positive behaviours such as healthy eating. Under the ‘main effects’ model, social relationships have a more direct protective effect on health through cognitive, emotional, behavioural and biological influences. The effects of loneliness are therefore substantial and can include higher cortisol levels, reduced protection against infection, increased risk of heart disease, higher blood pressure, disrupted sleep, greater levels of depression and even higher mortality (Bolton 2012). One study (Holt-Lunstad et al. 2010) has shown that having weak social connections is, in health terms, equivalent to smoking up to 15 cigarettes a day as well as being twice as harmful as obesity.

For people living with dementia, social interaction has specific benefits that can contribute towards a good quality of life, including reductions in agitation and other behavioural symptoms (Cohen-Mansfield and Parpura-Gill 2007). However, maintaining social contact can be particularly challenging for people living with dementia as well as their family carers. In a UK report (Alzheimer’s Society 2013), 33% of those living with dementia said they lost friends following a diagnosis and 39% said they felt lonely, compared with 24% of over 55s in general. The figure increased to 62% for people with dementia living on their own. The report called for greater understanding on the part of local government and other commissioners about the needs of people with dementia living within the community, and the provision of services to ensure that they are not socially isolated or lonely. Examples of how to support social interaction include dementia cafés, walking groups, befriending services and accessible transport to allow people with dementia to attend social clubs or other services.

In summary, for a number of reasons, including ageism, older people often experience an increase in loneliness and lose the direct protective effect on health that social relationships. The situation can be accentuated for people with dementia, an age-related condition, because of the frequent loss of friendships due to the stigma associated with the disease. Therefore, it appears that older adults who suffer from dementia are susceptible to loneliness due to the double jeopardy associated with old age and dementia status.



## 16.6 Research Funding

In the UK, government spending for medical research is increasing year on year, while spending on dementia research was £66 million in 2015. That is double the figure for 2009–2010, but it is important to note that much of this is on bio-medical studies that aim to find a cure for dementia. Relatively little is spent on psychosocial research that aims to improve quality of life for those living with dementia, which has potential to be more effective in the short to medium term in the absence of a cure. UK charities also make a substantial financial investment in dementia research, a figure of approximately £20 million a year. However, the total government and charitable spend on cancer research is almost 7 times greater, despite the fact that similar economic costs are associated with the two conditions.

It is also interesting to note that, in addition to impacting on the receipt of care and support, stigmatisation can be a barrier to participation in research (van der Vorm et al. 2008). This can be exacerbated by barriers imposed by gatekeepers towards people with dementia, often based on stereotypes concerning their communication abilities and their interests (Brooks et al. 2017; Sherratt et al. 2008).

## 16.7 Recent Changes and Potential Lessons Learnt

Recent years have seen a major change in how governments across the world approach dementia, largely driven by recognition of the personal, social and economic costs of the rapidly increasing numbers of people living with the disease. In many countries, this approach is based on a national plan, strategy or framework that aims to improve diagnosis, treatment and support. The majority of these approaches include dementia awareness campaigns, based on a recognition that the stigma that is widely associated with dementia can prevent people from seeking a diagnosis and therefore from having the opportunity to access appropriate care and support. This was captured in one of the recommendations of the ALCOVE project, which stated that ‘*Decreasing fear and stigma about dementia is a necessary precursor for increasing the numbers of people coming forward for diagnosis*’ (Brooker et al. 2014). Dementia awareness campaigns were reported by almost all countries provided for both professionals and the general public, but 32% reported a lack of legislation to protect people with dementia, and nearly 50% reported no legislation for advance statements/directives. Where legislation existed, it was often inconsistently implemented, supported or promoted particularly in the promotion of advance directives. This suggests that in many countries people experience discrimination in terms of the care and support they receive as a result of having dementia, in addition to any discrimination that occurs as a result of ageism. A total of 43% countries reported having specific policies in place to improve the quality of diagnosis. Countries that did have policies in place reported diagnosis being made at an earlier stage.



Attention on dementia has also been focused and coordinated through a range of international initiatives including the Paris Declaration, the G8 dementia summit, the World Dementia Council, the WHO global dementia observatory and a European Parliament declaration, all of which recognised the need to increase awareness and address stigma as part of the ‘fight’ against dementia. However, there is no evidence for the impact of policy based initiatives such as these.

Another initiative to reduce stigma and discrimination is the ‘dementia-friendly communities’ movement that has been adopted in several countries including the UK, India, France, Ireland and Canada (Wiersma and Denton 2013). In the UK, over 120 communities are now registered as dementia-friendly, using an overarching framework to monitor their progress. This covers a range of key areas: the involvement of people with dementia from diverse groups; challenging stigma and building understanding; ensuring an early diagnosis; providing consistent and reliable travel options; developing easy to navigate environments; and promoting respectful and responsive businesses and services. This movement overlaps considerably with the age-friendly cities and communities movement that has been led by the World Health Organisation (WHO 2007) with the aim of improving quality of life for older people and reducing ageism.

The independent sector has also made a significant contribution towards increasing awareness of dementia and tackling stigma. This has taken place at national levels, as demonstrated by the actions of the Alzheimer’s Society in England, and internationally through the work of Alzheimer’s Europe. Alongside this, in some countries there has been a growth in the dementia rights movement, which has seen the voice of people with dementia and their family carers become a major force for change in social perceptions of people with dementia and how they are treated within society, including by health and other public service providers. In the UK, this has been a key factor in a government commitment to enabling people to ‘live well with dementia’, particularly through the Dementia Strategy, the Prime Ministers Dementia Challenge, and the Dementia Friends approach. These initiatives appear to have led to a growing awareness of the need to raise awareness of dementia across society, to improve services for people living with dementia and the importance of adopting a truly person-centred approach.

## 16.8 Conclusion

The information presented in this chapter suggests that people living with dementia experience a double stigmatization, due to old age and dementia, which can lead to people feeling excluded from many of the activities that most of us take for granted. However, there are some important differences between general ageism and dementia stigma. For example, discrimination and stigma are based on judgements concerning a person’s characteristics and membership of particular ‘group’. Therefore, everyday ageism against an individual is often based on the perception that they belong to the group of ‘older people’. For dementia the situation is different because

it is not generally possible to tell that someone has dementia by looking at them. Therefore, the operationalization of stigma against individuals with dementia is usually only possible for those who have access to knowledge of their condition. This tends to be the professionals and organisations that are responsible for delivering health and social care services, but might also include friends, relatives and neighbours. Another important difference is that increasing age is often associated with some positive stereotypes, such as wisdom and high morals, whereas it is difficult to find any positive attributes that are commonly associated with dementia. It is also important to note that, as discussed in other parts of this book, widespread ageist views often lead to an assumption that older people have symptoms of 'senility', such as memory problems and other forms of cognitive impairment.

Swaffer (2014) puts it well when writing about stigma, language and dementia:

In short, social action is needed to ensure that we engage people with dementia, not just the wider community in understanding dementia and in that way reduce the social isolation, discrimination and stigma that people with dementia experience. We want to access services and to participate in the community the way everyone has a right to expect, and to have our disabilities respected with acceptance, support and enablement. (p. 714).

Finally, the study of ageism and dementia is relatively new and there is a need for more specific research in this area. Work of this kind will enable us to develop a more nuanced picture of discrimination and stigma in a range of countries and settings and to explore how it can best be addressed. Reducing stigma is a crucial element in the challenge of supporting people to live well with dementia and reducing the 'double stigma' that they frequently experience in addition to ageism.

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