
Addressing the Stigma associated with Dementia

Discussion Paper 2

September 2010



**Alzheimer's
Australia NSW**
Living with dementia

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Alzheimer's Australia NSW acknowledges the risks of 'labelling' as a result of this paper because it draws attention to the negative community responses people with dementia and their carers and families experience. However, there is a need to keep faith with the comments that argue there is stigma in the community and to highlight the evidence that suggests a discussion such as this is needed. Alzheimer's Australia NSW has treated this evidence sensitively and does not wish to add to the emotional burden already carried by people with dementia and their families.

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Executive Summary

Dementia doesn't discriminate and neither should weⁱ

Dementia is a condition that carries a heavy burden of stigma. People's attitudes, perceptions and understanding of the nature of dementia can determine how a person diagnosed with dementia, their carer and family accept and learn to live with the condition. The stigma associated with dementia can often lead to social exclusion, discrimination and disempowerment.

The downstream effect of stigma is profound. It affects a person's ability to seek help which, in turn, affects the process of early diagnosis and assessment as well as referral to services and support. Understanding stigma, its sources and characteristics is the critical first step to creating new ways to counteract its effect. It is an important step in the pathway to improving the lives of people with dementia, their carers and families.

The purpose of this paper is to raise public awareness about the effects of stigma associated with dementia, to address the need to change the way we, as a society, approach dementia, and to make recommendations for further action.

Dementia is the term used to describe the symptoms of a large group of diseases that cause a progressive decline in a person's functioning. The condition not only affects memory, but also intellect, rationality, social skills and emotional reactions. While a diagnosis of dementia is more common after the age of 65, dementia is not a normal part of ageing. People in their 40s and 50s are also diagnosed with younger onset dementia.

The number of people in Australia with dementia continues to dramatically increase. An estimated 257,000 Australians are currently diagnosed with dementia. Numbers are predicted to double to 565,000 by 2030 and almost double again to 981,000 by 2050ⁱⁱ. Currently 60% of people with dementia reside in the community; mostly cared for by family members but sometimes living alone.

Research literatureⁱⁱⁱ on dementia-specific stigma has only recently begun to emerge. This growing body of evidence suggests the pressing need to address the stigma that is embedded in community attitudes toward, and our social relations with, people with dementia and their carers.

To eliminate the stigma associated with dementia, community awareness campaigns cannot work alone. It can also be achieved by emphasising the retained abilities of a person diagnosed with dementia and their capacity to participate in a social life.

To help generate further discussion about stigma and its relationship to dementia, Alzheimer's Australia NSW carried out preliminary surveys of members of the general public, carers and people with dementia to investigate the notion of stigma and the attitudes of people about dementia. Findings have revealed significant evidence to suggest the presence of stigma and a lack of understanding of dementia:

- 61.3% of those surveyed did not believe the general public had an understanding of dementia;
- Dementia is the second most feared disease after cancer;
- 76.7% of carers stated they had at some time felt embarrassment or shame for the person for whom they care;
- People with dementia reported significant concern for the impact of stigma on their families;
- People with dementia called for recognition of their retained abilities to increase their capacity for social inclusion.

This discussion paper incorporates the results of those surveys and examines the notion of stigma associated with dementia, how it is manifested in society, and how it can be eliminated.

Recommendations in summary:

1. The Australian Government, as part of the National Dementia Initiative, develop and fund an ongoing National Dementia Awareness Campaign that aims to increase an understanding of dementia to decrease stigma;
2. The Australian and NSW Governments fund social inclusion initiatives such as leisure and access programs that recognise the retained abilities of people with dementia and enable them and their carers to participate in mainstream community life;
3. The Australian Government amends aged care legislation to include enforceable quality dementia care standards, such as those developed by Alzheimer's Australia, which can be applied across aged care services. These standards should include staffing, ongoing training and appropriate workforce qualifications;
4. The Australian and NSW Governments fund programs for early diagnosis and timely referral to dementia support services to avoid the impact stigma has in delaying access to diagnosis and medical support;
5. The Australian and NSW Governments fund and support dementia-specific education and training for all personnel working in dementia care services to reduce prejudice and stereotyping amongst dementia-care workers;
6. The Australian Government recognise the need to invest in further social research into the effect of stigma on the lives of people living with dementia, their carers and families.

Background

More than 250,000 Australians are currently diagnosed with dementia. Recent projections suggest this number will increase astronomically to 565,000 in 2030 and 981,000 people by 2050^{iv}. Currently 60% of people with dementia reside in the community; mostly cared for by family members, but sometimes alone.

Stigma is defined^v as a sign of disgrace or discredit that is considered to be undesirable by society. It defines the person who is the recipient of the stigma and sets them apart. A diagnosis of dementia not only profoundly changes the life of the person diagnosed but transforms the lives of the people who care for them.

The perception of dementia and what it means to these people will shape the way they live and cope with the condition and how they will interact and care for the person with dementia. The discrimination and perceived stigma that is often associated with dementia will be a challenge they will need to face. To alleviate this discrimination a greater understanding of dementia and the lived experience of people with dementia is required.

Health related stigma can be described as:

A social process or related personal experience characterised by exclusion, rejection, blame or devaluation that results from experience or reasonable anticipation of an adverse social judgement about a person or group identified with a particular health problem^{vi}

Despite growing recognition that people with dementia are socially disadvantaged, the negative impact of stigma has only recently been addressed. It has been suggested^{vii} that the perceived stigma associated with dementia is greater than some other conditions due to the related cognitive incapacities rather than a condition that manifests itself in physical incapacity. Furthermore, dementia is a progressive, terminal condition that primarily affects older adults later in life, which compounds the impact of stigma particularly in the early and middle stages.

The meaning of dementia is no longer constructed solely within the realm of a medical model whereby individuals are viewed through the lens of their disease.

The traditional medical view often defined a person by their illness which promoted dependence and often lead to loss of self-esteem. This medical model has today given way to a more holistic view of dementia that incorporates the social context of dementia such as the role of carers, a person's relationships with others and how the community responds to a person with dementia.

The holistic view of dementia enables a greater emphasis on the individuality of the person. The unique features of the illness and the impact it has on the individual are revealed by Tom Kitwood's statement:

Once you've met one person with dementia...you've met one person with dementia^{viii}

The social context of dementia resonates with the social model of disability^{ix}. Using World Health Organization guidelines, dementia as a disability is viewed as one of the most serious health and social care challenges facing the world today^x. It has been suggested that by incorporating dementia into the social disability model, social and environmental factors are highlighted alongside a respectful consideration of personhood and the individual's retained abilities rather than losses. While the debate continues around the notion of dementia as a disability^{xi} – and some still see disability in physical terms only – the influence of social factors such as stigma on the experience of dementia is similar in impact to the widely accepted experience of those with disability^{xii}.

The influence of stigma associated with dementia on an individual's basic human rights should not be ignored. Stigma can significantly negate a person's dignity and self-reliance. A diagnosis often means the person with dementia has limited control over their own lives, is often disregarded in decision making about their own care plans and 'ultimately their fundamental rights as citizens and human beings may be infringed'^{xiii}.

While it is understood that a person with dementia loses their capacity to make decisions for themselves over time, a social model of dementia would ensure a person's human rights are addressed. This would enable the person with dementia to continue to exercise their rights of citizenship and the basic human rights of respect, dignity and acceptance, both before and after they lose their ability to make decisions for themselves.

It was reported recently by Alzheimer's Australia Chief Executive Glenn Rees^{xiv} that Australia has made significant progress in the last 30 years addressing the social and medical issues that face people with dementia and their carers and family members. However, he stated, the time has come for a 'revolution' in the way we think about dementia as we still have a long way to go. One reason for this revolution is the persistent perceptions of stigma that are associated with dementia and the resultant fear, distress, and social isolation of people living with dementia.

Purpose

This discussion paper seeks to address the notion of stigma associated with dementia: to review relevant research literature; to investigate the manifestation of stigma and its consequences and; to provide alternatives to alleviate, and at the same time highlight, the barriers to quality of life that stigma creates for people with dementia and their carers. Ultimately this paper seeks to address the need to change the way we, as a society, approach dementia and our treatment of those living with the condition.

Alzheimer's Australia NSW Research Project

A research project was conducted by Alzheimer's Australia NSW in 2010 to determine current social attitudes about dementia. The results of this pilot study inform and address the need for increased community awareness about dementia to reduce stigma alongside a call to increase dementia literacy and the social inclusion of people with dementia.

Current literature

Research literature regarding dementia-specific stigma has only recently begun to emerge^{xv}. This growing body of evidence suggests several pressing needs:

- The need to address the stigma that is embedded in community attitudes toward, and our social relations with, people with dementia and their carers;
- The need to address the fear that surrounds the notion of dementia and increase community awareness and understanding about the condition;
- The need to increase opportunities for self-advocacy for people living with dementia and a need to include them in decision-making about service type, design and evaluation;
- The need for doctors and health professionals to recognise the importance of early diagnosis and support;
- The need for the media to recognise their social responsibility to portray real, balanced imagery and commentary;
- The need to further validate dementia as a National Health Priority in Australia by recognising the importance of social and medical research to enable better quality of life for all people living with dementia.

Methodology

A triangulated method of data collection (see Table 1) was employed to gather information from the general public, carers of people with dementia and people with dementia.

Table 1. Methodology

| 1. General Public | 2. Carers of people with dementia | 3. People with dementia |
|---|--|---|
| Over 180 people were interviewed at the Seniors Concert held in Sydney, March 2010. | 63 consumers from the Alzheimer's Australia NSW Regional Consumer Committees responded to a questionnaire conducted in April 2010. | Telephone interviews were conducted with six people with dementia (three males and three females) in June 2010. |
| Findings entered in the SPSS program for analysis. | Qualitative data was analysed using manual content analysis techniques and quantitative data was analysed using the SPSS program. | Data was analysed using manual content analysis techniques. |

Limitation

A limitation to the data collection was the age range of participants in the General Public cohort. Most people attending the Seniors Concert were between 61 years and 80 years with only 14 people aged 50 years or under.

Results 1: General Public Intercept Survey

- 92.2% stated they would like their doctor to tell them they had the symptoms of dementia 'as soon as possible';
- Dementia was the second most feared disease after cancer;
- 61.3% did not believe the general public had an understanding of dementia.

Of the 181 members of the general public who were interviewed 70% were female and 30% male. The ages ranged from 50-90 years and the majority found in the middle age groups of 61-70 years (43.6%) and 71-80 years (33%).

Initially the respondents were asked 'Do you know what dementia is?' and 91.5% replied that they did. However, when questioned further about the general public's understanding of the nature of dementia the majority (61.3%) did not agree the general public had an understanding.

When this cohort was asked whether they have ever known anyone with dementia 87.8% replied that they had. Hypothetically, the large response rate to this question was expected due to the age range of the participants at the Seniors Concert. However, it also suggests the large number of people living with dementia in our community.

Respondents to the survey were asked to choose which disease they feared most: 'cancer', 'dementia', 'heart disease', 'diabetes', 'other' and 'I don't really fear any disease'. Dementia rated second highest after cancer (see Table 2).

Indeed, the number of responses in these two categories was significantly higher in comparison to the other disease choices.

Of the 159 people who have known a person with dementia 134 (84.3%) replied that they had never felt embarrassed or ashamed of them. However, more than half of the respondents (57.5%) stated that they had witnessed other people treating the person with dementia in a negative way, due to their dementia.

Where a person resides is an important factor for consideration in the context of stigma and discrimination. Participants in the survey were asked 'where should people with dementia live?' and the results were a combination of 'in their own home' and 'in a nursing home'¹. Table 3 suggests that while a large number of people believe that someone with dementia should live at home there is also the belief that a nursing home is an inevitable final 'home' for a person with dementia.

This data correlates strongly with data from the question 'If you developed dementia who do you think should look after you?' Here more than half of the

respondents replied that spouse partner or family (52.1%) should be the primary carers and yet 40.4% responded with 'nursing home'². Anecdotal evidence from interviewers showed that many respondents stated they would like to stay at home for as long as possible but realised insufficient community support services, particularly in later stages of dementia would preclude this.

To ascertain the attitudes of this cohort about diagnosis and early intervention the participants were asked 'if you developed the symptoms of dementia, when would you want your doctor to tell you?' The majority (92.2%) of respondents stated they would like to know 'as soon as possible', 4.4% 'would rather not know until it became serious' and 3.4% 'don't know'.

When asked 'If you were diagnosed with dementia would you tell anyone?' A large majority of respondents (93.9%) claimed they would, even if it were only family and friends (53.3%).

For the small percentage (3.3%)³ who said they would not tell anyone the main reason was 'I don't want to be a burden'.

Lastly the participants in the survey were asked whether they had heard of Alzheimer's Australia NSW before and 83.6% replied they had. Of those, the largest number (45.2%) had heard about the organisation via the media⁴.

¹ The term 'nursing home' refers to residential care facilities. It was used in survey questions as current parlance and in other areas of this document when verbatim quotes were given.

² Other results from this question: 'Friend' 2.3%, 'I don't expect anyone to look after me' 3.8%, 'I don't know' 1.5%.

³ 2.8% did not know whether they would tell anyone.

⁴ 'Family or friend' 17.8%, 'Seniors event' 12.0%, 'Other' 13.0%, 'Doctor' 9.1%, 'Internet' 2.9%.

Table 2: Which of these diseases do you fear the most?

| Disease | Percentage |
|--|------------|
| Cancer | 41.3 |
| Dementia | 37.2 |
| Heart Disease | 7.1 |
| Diabetes | 4.1 |
| Other (blindness, stroke, Parkinson's disease) | 3.2 |
| I don't really fear any disease | 7.1 |
| Total | 100.0 |

Source: AlzNSW General Public Survey March 2010

Table 3: Where should people with dementia live?

| Place | Percentage |
|-----------------------------|------------|
| At home | 35.5 |
| Nursing home | 19.8 |
| At home – then nursing home | 39.6 |
| Hospital | 1.7 |
| Don't know | 3.4 |
| Total | 100.0 |

Source: AlzNSW General Public Survey March 2010

Results 2: Carers’ Self-Reported Questionnaire

- 90.5% would like their doctor to tell them if they had the symptoms of dementia ‘as soon as possible’;
- 93.3% stated they would tell other people if they were diagnosed;
- 76.7% stated they had at some time felt embarrassment or shame for the person they care for.

Overall 93.3% stated they would tell other people if they were diagnosed, with 51.7% stating they would tell family and friends only. For those that might choose to keep the diagnosis a secret the reasons for doing so were primarily based upon the notion of being a burden to others, rather than shame or embarrassment.

Who should look after you?

Sixty three carers responded to the consumer survey. Eighty four were female and 16% male. The age ranges were under 65 years (37.1%), 65-74 years (43.5%), 75-84 years (16.1%) and 85 years and over (3.2%).

When asked who they expected to look after them if they developed dementia, Table 4 indicates ‘nursing home’ (37.6%) as the first choice for respondents, closely followed by ‘family’ (26.6%) and ‘spouse/partner’ (21.1%). Other responses included ‘I don’t expect anyone to look after me’ (5.5%) and ‘friend’ (1.8%) while 7.3% said ‘I don’t know’.

More than half of the carers were caring for a spouse/partner (52.4%). Others were caring for a parent (12.7%), another family member (3.2%), a friend (3.2%), were former carers (27%) and one person (1.5%) was caring for both a parent and a spouse with dementia.

Table 4: If you developed the symptoms of dementia, who should look after you?

Where should people with dementia live?

| Carer | Percentage |
|--|------------|
| Nursing home | 37.6 |
| Family | 26.6 |
| Spouse / partner | 21.2 |
| I don’t know | 7.3 |
| I don’t expect anyone to look after me | 5.5 |
| Friend | 1.8 |
| Total | 100.0 |

The majority (59.7%) of respondents to this question believed that a person with dementia should live at home while 33.9% believed that the best outcome was for the person to live at home and then transfer to a nursing home. In comparison to the general public survey this cohort had fewer respondents choosing the nursing home option as the only option.

The diagnosis of dementia

When respondents were asked how soon they would like a diagnosis if they presented symptoms of dementia the results were similar to the general public cohort. An overwhelming 90.5% stated they would want to know as soon as possible.

Source: AlzNSW Carers’ Survey 2010

Family and spouse/partner could be classed together as 'family' in some cases, however, the large number of responses that indicated preference for care in a nursing home suggests the desire to minimise burden on the family.

Shame and embarrassment

Amongst those that responded (60) to the question about feeling embarrassed or ashamed of the person they care for, 76.7% respondents stated that they had at some time felt embarrassment or shame for the person with dementia, while 23.3% claimed they had 'never' felt this way.

This finding provides a significant comparison to the 84.3% of general public respondents who 'never' felt shame or embarrassment toward the person they knew with dementia and highlights the unique and close relationship a primary carer has with the person with dementia.

Breaking social norms

The qualitative data collected in response to the notion of embarrassment and shame for the person with dementia and for the carer outlined a variety of contributing factors.

Carers reported times of embarrassment, for themselves as well as the person with dementia when the person with dementia breaks social norms that are deemed respectable and appropriate. Reports included insulting remarks to people about their appearance, bad table manners, wearing dirty clothes and using foul language.

I guess it was because the behaviour that caused the embarrassment was public, totally out of character with pre-dementia behaviour and the witnesses had no idea of the cause of the behaviour (carer)

Her language has become like a 'fishwife'. Even though I have explained these things to people, I feel it makes it difficult for the other people – and anxiety for me (daughter-in-law)

Carers as protectors

Carers 'covering' for the person with dementia and explaining the situation to relieve others' anxiety and distress were common scenarios reported in the survey.

There is no warning most of the time. I have to be vigil (sic) in order to protect him from embarrassment, especially in the company of those with no understanding of the condition (carer)

My husband had a 'thing' about overweight females and would point and say 'would you look at that' so I always carried a card from Alzheimer's explaining his disability (carer)

Some carers explained how they would let others know about their loved one's condition before a social occasion so that there would be greater acceptance and another told of calling a friend to explain her husband's condition after he had behaved inappropriately during a dinner.

If I explain prior to a social occasion, my husband's 'malady' he is accepted as an equal and not ostracised (carer)

Some carers spoke of physically moving the person with dementia away from a situation if they felt he or she was causing discomfort to others. Other spoke of the social isolation that had resulted from their avoidance of social situations that might cause themselves, the person with dementia or other people embarrassment.

[I] felt some embarrassment on behalf of the person as I know he would not have put himself in this position and to protect him I avoid the situations out of respect for the feelings he would have felt (carer)

He was aware that people thought him strange (carer)

Person with dementia is healthy and gets very upset with his Alzheimer's and embarrassed. He considers himself a 'fruit loop' (carer)

The built environment

Carers reported that the built environment is not always conducive to the needs of a person with dementia and this can cause embarrassment for both the person with dementia and the carer. Incontinence is a common concern for a person with dementia and the location and accessibility of toilets in public spaces, such as shopping centres, is not always ideal. Reports were made about the inability to accompany a person to the toilet if a 'disabled toilet' was not available and others stated that the physical appearance of someone's incontinence due to the unavailability of appropriate toilet facilities can be a cause for embarrassment.

One carer complained about residential care facilities and the 'strong characteristic odour that meets you before you even open the door of the facility' as a cause for her embarrassment for all people with dementia, not just the person she cares for.

Negative attitudes and stigma associated with dementia

Extensive qualitative data was collected regarding the negative attitudes of other people in the lives of people with dementia and their carers. Survey participants were asked to describe their own experiences of stigma as carers of people with dementia.

Comments were made about the concept of denial, which reinforced the notion of carers as protectors of those with dementia.

My husband was against telling anyone, including family (carer)

Some carers were forced to deny the diagnosis by the person they cared for, yet others asserted the benefits from disclosing the diagnosis as early as possible stating that once people understood, the situation often improved.

Community education is needed and the best teacher is the carer (carer)

More than one respondent claimed the carer's positive or negative attitude was integral to the way the person with dementia is treated. A sense of negativity following a diagnosis of dementia is often the cause of denial for some carers and 'only makes it more difficult for themselves and the ones in their care'^{xvi}.

Don't be afraid to ask questions and you should expect to get 'proper' answers. Don't be 'fobbed off' (carer)

Carers reported others 'with no experience in living with dementia'^{xvii} being critical of their care of the person with dementia. Many acknowledged that there needs to be increased understanding of the behaviours of people with dementia concomitant with

an understanding of the role of a person caring for someone with dementia and the specific difficulties they encounter, often alone, on a daily basis.

Social Isolation

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

Many carers reported covert negative attitudes expressed by others. The term 'contagious' was reported more than once by carers to describe the reason friends stayed away.

It's as if it's a highly contagious disease...they don't know much about the disease and don't know how to respond (carer)

Friends of the person with dementia stop visiting and others reported people avoiding them in the street, shopping centre or the doctor's surgery.

I have seen on some days people we know give my husband a 'wide berth' – he is unaware (carer)

Friends stayed away and treated the person as 'contagious' (carer)

People do avoid you (carer)

Old friends [of the person with dementia] stopped calling and visiting (carer)

The role of the primary carer is intrinsically woven into the life of the person with dementia. While many carers spoke of good support from their friends, and one told of only losing 'his' friends not 'mine', the findings suggested that social isolation for the person with dementia can also have a strong influence on the life of the carer.

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

Feelings of sadness and sympathy were also described by carers for the person with dementia as the loss of friendships had meant a loss in social stimulation and self-worth for the person.

They need to be treated with dignity and respect just like anyone else; not treated like they don't know anything (carer)

In order to address stigma for people living with dementia we need to find the means to facilitate their social inclusion. They need support and greater opportunities for participation in economic, social and cultural life. They need to know they have the right to dignity and self determination.

Reasons for avoidance

I feel people are apprehensive to make contact because they are ill-informed about the disease, dementia, and do not know what to say (carer)

Fear, pity and lack of information were reported consistently in the data as the reasons that many people avoid a person with dementia and their carer. There is little community information and understanding about communicating with a person with dementia and due to limitations in the knowledge of dementia behaviours many people are afraid they will say or do the 'wrong' thing, which may result in an adverse reaction.

Friends have dropped off because of their lack of coping (carer)

The attitude of awkwardness is fuelled by the feeling they may say or do the wrong thing, thus adding confusion to the already complex situation (carer)

There was significant evidence that a lack of appropriate communication skills were related to the avoidance of social settings that included people with dementia and their carers.

I have taken Mum to functions and no one comes to talk to her. She may not be able to start a conversation but is very chatty if someone talks to her (carer)

On the contrary some reported friends who were patient, inclusive and kind; who treated dementia as an illness just like any other.

Family

There was strong evidence of the role that family played in the lives of the person with dementia and the carer's response to this.

They have trouble coping with the loss of the person they used to know. Our son often doesn't want to speak to his father because he claims 'it's pointless...he forgets anyway!' (carer)

Some spoke of family breakdown and others of family members who refused to accept the person's diagnosis of dementia. Two carers from cultural and linguistically diverse (CALD) backgrounds described the bind they felt as carers and expressed the need for awareness about diversity amongst families to reduce different types of stigma associated with dementia.

My ethnicity demands I be there all the time to the point that I now have depression and anxiety (carer)

Others spoke positively of the support they had received and the value of having family members nearby.

Community

I still find people in general are very ignorant regarding dementia and some continue to make jokes about it. Dementia is not a joke (carer)

Community attitudes toward people with dementia were varied. Amongst smaller communities, such as a retirement village where the person's diagnosis of dementia was acknowledged, the stigma appeared to be less. However, most of the findings provided significant evidence of stigma within community settings.

He engages in conversation with strangers and cannot carry out a conversation which makes sense. They laugh and walk away (carer)

I explained my husband's problem; the answer was 'if you are going to have an idiot on the street put a muzzle on him' (carer)

Most carers attributed a lack of understanding as the reason the person with dementia sometimes received negative reactions from people in the community and consequently, the cause of the person becoming excluded from community life.

Doctors and other health professionals

Both carers and people with dementia reported significant evidence of stigma associated with dementia in their relationships and experiences with doctors and health professionals.

Carers described particular notions of stigma during the period pre-diagnosis. They spoke of being 'fobbed off' by doctors who did not believe their concerns about their loved ones and, who seemed unaware of the unpredictable nature of dementia that enables a person with dementia to appear 'good' one day and 'bad' another.

In the medical community dementia is a word that is not talked about as it means to be demented (mad). It is treated almost as a stigma as if the family should or could have done something to prevent it happening. Most people do not want to talk about it and still regard it as something that happens to old people (carer)

Others spoke of the inadequate understanding of the nature of dementia amongst health workers, residential care and respite workers. They described situations where the worker would speak about the person with dementia in their presence without acknowledging them and use generic stereotypes to describe all people with dementia.

Just recently in hospital referring to a room kept for people with behaviour problems [the] nurse said that is where we put the 'crazies' (carer)

The worst aspect is the unrefined 'blanket' approach of treating everyone with dementia as if they don't understand anything, and using it as an excuse to ignore requests (e.g. toileting) and respect basic rights because they [are] in vulnerable positions, unable to protest [and] fear abuse (carer)

Another respondent described the respite workers who came to her home to care for her mother:

Several ladies were wonderful, talked to Mum, and asked her to 'help' so Mum had things to do. Others just came in did washing [and] cleaning and left without talking (carer)

Younger onset dementia

People with younger onset dementia experience stigma but often in a different dimension to older people. These dimensions include economic, social and emotional issues such as employment, dependent family members, retained physical fitness and, in most cases, a younger carer. Case Study 1 exemplifies this last dimension.

Case Study 1: Female carer of both husband and mother with dementia

'In the last five years Mum [was] diagnosed at 61 and my husband at 54 and caring for them both with dementia, I have learnt a lot. This disease is not understood, generally by the public; it is seen as an old person's disease. I have encountered rudeness from doctors and people have even argued with me that young people don't get dementia; even family members who are given the diagnosis written down by a

continued next page

specialist, still will not believe that the person has dementia. Other... carers or people who have been involved with dementia understand.'

'Thankfully Alzheimer's Australia and the respite services are there to help and understand the impact of this disease both emotionally and financially. As a carer, my future isn't looking too good; I know in order for me to survive financially, I'll end up having to sell our home in order to pay for full time care, due to my age.'

Discrimination in the workplace was reported by both carers and people with younger onset dementia. Often a person was asked to leave their employment upon diagnosis without any discussion about possible alternatives. The repercussions for this sort of treatment were reported by carers and people with dementia who had dependents, thus transferring the stigma to them.

My husband wanted a job while he could still do something but no one was willing to 'give him a go' even when he could have done something careful with supervision. Self esteem plummeted (carer)

Lack of earning power holds a large stigma in the earlier stages (carer)

Another concern for people with younger onset dementia is the notion that they are too young for dementia. Respondents claimed that it was difficult to deal with this type of discrimination as the denial of the existence of dementia amongst health personnel, friends and family made the role of the carer more difficult and often encouraged the person with dementia to enter a state of denial.

People who don't know him intimately make comments to him like 'there is nothing wrong with you, mate!' which causes him to subsequently go into denial (carer)

One person with dementia reported that she visited a medical specialist due to a complaint unrelated to her dementia and had to produce her prescription for her medication to confirm she had been diagnosed with dementia. She also spoke of avoiding the topic of her condition as she no longer wanted to hear people's reaction to her diagnosis at such a young age.

The importance of good information

Many carers stated their feelings of embarrassment or shame were often the result of misinformation or lack of information about the condition of dementia. Some reported that family and friends felt better and were more understanding once they were informed of the person's condition. Others also claimed their own coping and management skills were enhanced once they had availed themselves of support services.

After my training at Alzheimer's I always took these things in my stride and told people of the problem (carer)

Similarly, when reporting negative attitudes and discrimination from others in the community, carers and people with dementia believed this could be reduced if community awareness and education about dementia was increased. Some carers, and all of the people with dementia, claimed that this information is enhanced by experiential learning; that is, the experience of living with people with dementia in the home, in the community and in society.

The general public is ignorant of dementia, as I was; unless you are involved you don't understand (carer)

Friends with no experience in living with dementia have been critical (carer)

Unhelpful attitudes usually occur when people are ignorant of what is happening; wide public information is needed (carer)

Respondents spoke about younger family members and their need to be educated about dementia. Some reported that community awareness should include a wide audience and be appropriate for young people as much as those in older age groups.

We feel that education programs need to begin in school education; children generally have very little understanding of the condition. They understand physical (visible) disabilities; they are capable of understanding mental disabilities (carer)

There were concerns by some respondents that health promotions which focus on reducing the risk of dementia by promoting activities such as exercising, socialising and keeping your brain active, could be misinterpreted as 'preventing' dementia and thereby increase the stigma on those who ultimately develop the condition.

The public may well conclude that someone who gets Alzheimer's may be not very intelligent, not a sociable person, someone who hadn't taken care of him/herself. Therein lies a major source of stigma (carer)

Other carers believed dementia initiatives could follow the pathway used in mental health initiatives. Successful promotions in this area have negated the blame for mental health somewhat from the person living with the condition, and increased the community awareness and understanding surrounding issues such as depression, bipolar disease and postnatal depression.

Branding

Comments on branding and symbolism were also reported in the findings and the development of stigma. The notion of a universal symbol was reported and one carer reported wearing the Alzheimer's Australia NSW elephant badge to increase community awareness.

Some carers believed there is stigma attached to the term 'dementia' and its connotations of madness. At the same time, others reported the term 'Alzheimer's disease', which has memory loss as a symptom, causes stigma and discrimination for someone diagnosed with another form of dementia, whose initial symptoms may not include memory loss, such as frontal lobe dementia.

Results 3: Telephone Interviews with the Person with Dem

I didn't do this deliberately! (person with dementia, 72)

- Significant concern for the impact of stigma on their family;
- Findings of 'masking' and withdrawal in social situations;
- Most reported medical and health professionals were negative in their outlook;
- Call for recognition of the retained abilities of a person with dementia to increase capacity for social inclusion.

Six people with dementia were interviewed and key issues emerged that provided evidence for the stigma associated with dementia. Respondents reported they often 'masked' their symptoms of confusion, disorientation and memory loss, to negate embarrassment for themselves and those around them. All were aware of their condition and the stigma associated with it although two people stated they were not always aware of it in their own lives.

Family

Most of the people with dementia spoke of their concern for their family, the embarrassment they may have caused them and the burden they feel they have become. Some of the people with dementia reported their concerns for their children who were upset with their parent's diagnosis and aware of their diminished capacities.

Case Study 2: Jenny (a person with dementia)

Jenny received a lot of negative comments about her condition from friends and family; not in a derogatory way but unhelpful negative remarks such as 'how depressing', 'don't you get upset about the diagnosis?' Jenny said this upsets her and has meant she is in denial about her condition most of the time 'until someone confronts me about it'.

She believes her children are also in denial although she knows that they are aware that her capacity is diminishing and they will need to help. She does not cope with change and can no longer handle the process of making dinner. Her children assist her in this and also, at her request, have begun to drive her rather than she drive as she knows that eventually that will be the case for them permanently.

Of those that had a carer, acknowledgement was made of their support and in some cases the person reported that they felt the carer probably felt the sting of stigma more. One person said of his wife:

It makes me sad that I have made the end of her life miserable (person with dementia)

This cohort were all aware of the wellbeing of their carer and one person reported she was glad to receive the services of respite care as it gave her husband a chance to play golf and enjoy himself.

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Social Isolation

The interviewees all maintained that social isolation was a factor in their lives and even those with sympathetic family and friends acknowledged that a lack of understanding and communication was an issue. For some, hurtful and unhelpful comments were made about the diagnosis of dementia which increased their avoidance of social situations. One person was told they were 'a stupid thing' and another with younger onset dementia was constantly told 'you don't look like you have dementia'.

Case Study 3: Martin (a person with dementia)

Martin says that when dealing with people who know about his dementia they often stereotype him and do not realise the different presentations of dementia.

They have a good circle of friends but are definitely more socially isolated than before his diagnosis. This is due to some friends no longer calling, due to their fear of not knowing how to communicate with him. Also he said that when he is in a crowded social situation he 'masks' his symptoms of confusion or else just stops participating due to embarrassment. He now avoids these types of situations.

Medical and health professionals

The stigma emanating from misinformation amongst health professionals was evident in the findings with this cohort. More than one claimed that the diagnosis of dementia took some time due to the doctor's disbelief of the patient's symptoms. Another claimed the doctor was very 'clinical' in his prognosis and did not offer any support or advice

about the capabilities she still possessed. Most reported that medical and health professionals were negative in their outlook about the diagnosis.

Reports were also made about counsellors and support providers who claimed to have an understanding of dementia but whose actions denied this.

A little bit of knowledge can sometimes be dangerous (person with dementia)

All respondents believed that increased dementia training for care workers and health professionals was imperative.

A badge for people with dementia

During the collection of data for this project a carer suggested the idea of a badge for people with dementia to wear which could be similar to that which can be worn by a person with vision impairment. It was suggested this would increase awareness and enable others to treat the person with dementia in an appropriate way. This idea was put to the interviewees and the responses were varied.

Some reported that they would be happy to wear a badge, one proclaiming he would be 'proud to wear it as a badge of honour for the other people with dementia'. Others did not agree believing it would be seen as a label, increasing stigma and the stereotypical responses that negate the capabilities that people with dementia still maintain.

Community Awareness

The more people know about it the less there is to fear (person with dementia)

All interviewees believed there needed to be an increase in community education to reduce the stigma associated with dementia to enable greater social inclusion for people with dementia.

As reported by the carers, this cohort also emphasised the advantages of 'knowing' a person with dementia. One interviewee claimed that an awareness campaign needed to 'personalise' the condition rather than 'fearing the abstract notion of it [dementia]'.

Case Study 4: Geoff (a person with dementia) and Sue (his wife and carer)

Sue reported that she does however feel the gaze of others at the doctor's surgery and that she sometimes thinks she would like to put a sign on the doctor's door saying 'Geoff's illness is not contagious'.

Both Geoff and Sue believe that there still is stigma in the community due to 'fear of the unknown'. They both feel that a community awareness campaign would educate people about dementia and help increase understanding about the condition. Sue said the 'heredity factor' was a big thing for a lot of people. 'Most people don't want to know about it,' but, she continued, 'more people need to be more upfront [about living with dementia].'

Discussion

Stigma leads not only to difficulties and delays in accessing services but also to exclusion from mainstream society^{xviii}

The impact of a diagnosis of dementia, alongside the negative responses of other people to the diagnosis and symptoms, can profoundly affect a person's emotional, social and psychological wellbeing and quality of life. A diagnosis may bring grief over loss of identity and status, low self-esteem, stigma and discrimination. This perceived stigma, whether experienced by the person themselves, their family or the community, can have the impact of relegating the person 'to a new lower status social group and results in social dislocation'^{xix}.

Stigma plays an important role in defining the way a person with dementia experiences dementia. With this in mind it has been suggested^{xx} that a social model of dementia rather than a medical model, is better suited to challenge stigma and discrimination. A social model illuminates the social experience of the person with dementia. It considers the contribution of relationships with others and social institutions within the experience. This includes the economic, political, cultural and environmental barriers they encounter. By using this framework the clinical diagnosis of dementia is not the only cause for concern with regard to stigma but also, the way in which society responds to those people who have been diagnosed. Rather than attempting to normalise the loss of cognitive capacity for the person with dementia there should be a greater focus on the recognition of the person's retained abilities for positive socially inclusive outcomes.

Fear

Fear of dementia was evidenced in the research and confirms the existence of negative and distressing perceptions that construct the notion of stigma associated with dementia. Responses from the general public found that dementia was the second most feared disease after cancer. This finding replicates those from a recent study in Canada that found Alzheimer's disease is the second most feared disease after cancer^{xxi}. Further, recent research by Neuroscience Research Australia reports that more than half of the young adults they surveyed feared 'dementia', 'Alzheimer's' or 'Parkinson's disease' for themselves or someone close to them^{xxii} and results from a recent study by Bupa Carer Services in Australia claim:

Australians are more concerned about diseases that affect mental capacity, such as dementia, than they are about stroke and heart disease^{xxiii}

Research indicates that fear about dementia emanates from:

- A lack of education and information amongst the general public;
- The unpredictable nature of dementia;
- Not knowing how to communicate with a person with dementia;
- Myths about 'catching' dementia by association;
- Notions of inheriting the condition from a family member.

The different dimensions of fear lead to avoidance of the person with dementia and their carer, and avoidance of discussing the topic of dementia.

Evidence indicates^{xxiv} some doctors and health professionals avoid discussing and treating issues that impact on the lives of their patients with dementia. They are often reluctant to support the patient as he or she deals with the distress of a diagnosis and the experiences of grief and loss that will come with a chronic and terminal health condition such as dementia.

I say slight cognitive impairment.
I never use the word dementia
(doctor)^{xxv}

Carers

'Courtesy stigma' is the term used to define the negative impact that results from association with a person who is stigmatised^{xxvi}. Just as the experience of stigma reduces social inclusion for the person with dementia, it also affects the livelihood of the carer. Due to the progressive decline of the person with dementia and their need for support, a carer's life and experience is directly and profoundly affected by the stigma associated with dementia.

The carer's life undergoes redefinition and the impact of courtesy stigma can include social isolation, loss of friendships, embarrassment and low self esteem. The domains of stigma that most affect a carer are the experience of stigma in social relationships (both intimate and professional), in social structures such as policy and legal regulations, within the bureaucracy of health care, within some support systems and in the experience of stigma in the domain of public images and media^{xxvii}.

The need to address the perceived stigma and discrimination felt by carers of people with dementia is an important concern. Positive support and opportunities for quality of life should be accessible, timely and appropriate.

Diagnosis

For people in the early stages of dementia, the awareness of the impact of the illness as it progresses and the responses of others toward them are acutely felt. For some time, it was assumed that these people had no insight into the effect the disease has, and would have, on their lives. However, there is growing evidence that people with dementia, especially in the early stages of the condition, do retain awareness for some time. It is this capability which leads to actions of self-protection such as attempts to hide the symptoms and sensitivity to the reactions of others toward them^{xxviii}.

With this in mind, the importance of early diagnosis and intervention for people with dementia cannot be underestimated. It enables the person with dementia to participate as much as possible in their own care plan, their financial and living arrangements for the future and, ultimately, how they would like to die. This important stage is often denied due to the perceived stigma associated with dementia and the reluctance to obtain a diagnosis.

Case Study 5: Margaret (a person with dementia)

Margaret has a background in health and was aware of dementia and what it entailed. She was advised to give up her job upon diagnosis by her doctor and was not happy. He told her that she would not be able to dispense medications in her role as an aged care nurse but, she complained 'everyone knows that's why you have two people doing that job, so that each can check the other'. She currently works as a volunteer.

General Practitioners

The GP is usually the first health care provider to be accessed by a person with concerns about their cognitive capacity. It has been suggested^{xxix} that three variables predict the practice of early diagnosis amongst GPs:

1. A belief in patient benefit from early diagnosis;
2. The possibility of negative outcomes from a failure to diagnose early;
3. Local support service accessibility.

Recent research^{xxx} indicates that GPs can find it difficult to assess someone with dementia when the patient 'covers up' or 'masks' their symptoms, often in collusion with the carer or family members. GPs report that 'not presenting' due to fear of the implications of a diagnosis of dementia is one of the greatest barriers to an early diagnosis of dementia.

There's that general social denial...it reinforces the fact that somebody is getting older – mentally as well as physically – and I think that's one of the biggest barriers (doctor)^{xxxi}

GPs are aware of the stigma associated with dementia and often believe they can relieve the person with dementia of the negative effects of stigma by delaying a diagnosis, especially if the patient appears to be managing^{xxxii}.

Many GPs see little advantage in disclosing diagnosis for an incurable condition for which they have no answers^{xxxiii}.

GPs need to be aware of available support services in their local area that can assist both the person with dementia and the carer, alongside knowledge of risk factors for dementia such as its association with cardiovascular health.

It is essential that GPs realise how important they are in the overall experience of dementia for their patient and the vital role they play as an agent of positive support.

Health professionals and care workers

Workplace facilitation and mentoring is crucial to transfer of information^{xxxiv}

Amongst the data in our study and other research there was evidence that health professionals and care workers are often implicated in the perpetuation of stigma by disparaging remarks and behaviour toward the person with dementia in a residential care facility, day centre or in the home. This denotes a lack of understanding about the nature of dementia and the need to increase dementia literacy and training amongst these workers.

While dementia-specific education provides knowledge, often theoretical, this alone does not ensure the application or transfer of that knowledge in the workplace. Appropriate follow-up training should be part of any educational program to reduce stigma amongst management, health professionals and care workers.

Care workers are 'sent' to be educated and then denied the opportunity in the workplace to implement their knowledge and skills; this is one area where a top-down approach would go a long way to remitting the 'stigma' attached to dementia^{xxxv}

A person-centred care approach is one which has favourable outcomes and can help maintain the dignity and self-determination of the person with dementia for as long as possible. It has the capacity to reduce homogenous and stereotypical responses to the person with dementia and it promotes a concept of care that has a holistic focus on the individual's personality and history, not just on managing the disease.

A barrier to service access

Alzheimer's Australia NSW promotes the benefits of early diagnosis and intervention to enable the best quality outcomes for all people living with dementia. However, the presence of stigma, due to fear and negative stereotypes, is often a barrier to service access and delivery. As reported, initial denial of the condition, by doctors, patients and carers can negate the opportunity to access information about the location and availability of services.

Good support networks are imperative to the health and wellbeing of carers. Recent research by Alzheimer's Australia NSW^{xxxvi} into the carer support group network in New South Wales found that stigma and shame attached to the diagnosis of dementia had prevented some carers from 'coming out' to access the benefits of a support group.

Notions of stigma need to be addressed before and immediately after diagnosis to break down barriers to service access. Community awareness about dementia that normalises its existence in the community needs to be widespread and easily understood and, following diagnosis, immediate support, such as contact with a Dementia Advisor, should be offered to every patient and carer to provide appropriate service information and reduce potential social isolation.

Shame and blame

Our research highlighted the fact that many carers felt the stigma of blame attached to the person with dementia after their diagnosis. As reported, respondents identified suggestions by others that perhaps the person with dementia had not lived a healthy, socially active and mentally stimulating life and so the diagnosis was their fault. Low and Anstey^{xxxvii} also report that many participants in their research on dementia literacy attributed dementia risk to personal characteristics such as 'weakness of character' and 'laziness'.

Findings in the Alzheimer's Australia NSW research suggested inherited genes are also blamed for the diagnosis of dementia and described the consequent guilt felt by the person with dementia who may have passed the gene onto their offspring.

Misinformation is often the cause of stigma, therefore, information that is easily understood should articulate the known causes of dementia, the very rare genetic causes of dementia and the important features of risk reduction. This information should be available across all media to infiltrate everyday parlance.

Ageism and dementia

Stigma around dementia doesn't always stand alone as a source of discrimination. Society's pervasive emphasis on youth and independence inadvertently creates a perceived stigma towards those who are ageing and dependent on others.

Ageism, which is the manifestation of age discrimination, is:

An ideology, which condones and sanctions the subordination and marginalising of older people within society and legitimises poor quality care, neglect and social exclusion^{xxxviii}

Milne (2010) reports that an ageist attitude disregards the autonomy and decision-making capacity of people with dementia and reports of 'abuse and neglect, premature institutionalisation and inadequate care' of people with dementia have implicated this attitude^{xxxix}.

Our study found reference to this dual stigma dilemma, especially amongst those in the early stages of dementia and those with younger onset dementia. This dual stigma has been coined the 'double whammy'^{xi} and may contribute to the misguided belief that dementia is a natural part of ageing. The perception that dementia is *inevitable* in old age contradicts the important messages of risk reduction, including associated health concerns such as diabetes and hypertension. It denies the need to understand varying dimensions of life with dementia and the effect the condition has on a person's economic and financial wellbeing. Further, it denies the retained capacities of people with dementia particularly those who are physically fit and it denies the belief that all people should have the opportunity to participate as best they can in an inclusive society.

This finding emphasises the critical need to address stigma alongside other related sources of discrimination when promoting risk reduction interventions and early diagnosis strategies.

Ethnicity and dementia

To understand the manifestations of stigma in the lives of people with dementia and their carers from Aboriginal and CALD backgrounds we also need to address the cultural beliefs and experiences that contribute to perceptions of stigma associated with dementia. In some cultures the cause of dementia is linked to religious explanations such as punishment from God or evidence of a curse^{xli xlii} while others normalise dementia within an ageist attitude.

In this situation, where the context of dementia is rooted in cultural, historical and religious experiences the person with dementia and family members are caught within multiple modes of stigma, often based on blame and shame. This results in concealment of the condition thus limiting the opportunity for diagnosis, access to treatment and social support.

Improvements in culturally sensitive support and service delivery have been made but need to be expanded. Further attention needs to be paid to the way people with dementia and their families from Aboriginal and CALD backgrounds are perceived by their peers and how these consumers can effectively participate in service design, delivery and evaluation.

Media and messages

Popular images of dementia represented in the media often depict people in the later stages of dementia. These include stereotypical images of people with dementia characterised by vulnerability, lacking in capacity and unable to cope. Documented accounts of people living with dementia use terms such 'dark', 'lost', 'tragedy', 'dread' and 'demented' rather than words that describe a person

living with dementia who still has the capacity for active social engagement. These images have 'undoubtedly been fuelled by ageist assumptions, the medicalising of dementia and labelling'^{xliii}.

Stereotypical images can be linked to discrimination as well as genuine misunderstandings about the nature of the disease. These images are difficult to eradicate but can be relieved by promoting positive images and accurate information to the media about the nature of the disease. An approach that also incorporates a message about maintaining the dignity and self determination of people living with dementia is also important. Indeed, the *Out of the Shadows* report^{xliv} suggests the increasing numbers of people diagnosed with early stage dementia provides the media with scope for a more holistic picture of the impact and diverse experience of dementia.

Policy and research

Our standing as human beings and societies will be judged by our response, not only to global warming, but also to the challenges of ageing and dementia^{xlv}

Dementia was made a National Health Priority in Australia in 2005, and in 2006 the Government funded the National Dementia Initiative to provide funding for dementia research and services across Australia. However the Dementia Initiative does not currently include a national community awareness campaign to address the issue of stigma and challenge misunderstandings.

Weiss and Ramakrishna (2006)^{xlvi} and others^{xlvii} highlight the importance of sound research from disease-specific as well as culture-specific perspectives to enable good public policy. Research should document social change,

comparisons with other disease stigmas, risk reduction and the burden of stigma, and promote the importance of a clear, simple message when dealing with complicated health problems. If these directives are explored, public policy interventions to reduce the stigma attached to dementia will be more appropriate, timely and effective.

Compared with \$160 million for cancer research, the combined research funding for dementia in Australia was \$22 million for 2007–09^{xlviii}. Now, with the development of new national health and aged care reform agendas it is critical the Australian Government address sustainable funding for research into dementia, including the origins and effects of stigma associated with dementia, or risk undermining the effectiveness of public policy.

Services and Support

To relieve the effect of stigma associated with dementia a greater focus is required on the development and delivery of services and support to enable a person with dementia to 'live an ordinary life'. Flexible support packages to assist people with dementia to maintain family, social and community relationships should acknowledge individuality and personhood. Appropriate support would enable continued participation in family rituals and leisure activities, and participation in tasks where the person with dementia can gain the sense that they are making a valuable contribution.

Supportive communities that include people with dementia and normalise their participation are critical to reducing stigma. The National Gallery of Australia's Dementia and Alzheimer's Outreach Program is a fine example of social inclusion. It facilitates community access for people with dementia and has brought new meaning and understanding to the lives of all

participants, the carers, the gallery staff and the people with dementia. The evaluation of the pilot Art Gallery Access Program proclaims:

The program was a social, sensual and intellectual experience...the fact that people with a range of levels of dementia could take part in and enjoy what, for many people without dementia is a normal activity de facto means that the program is successful and worth repeating and expanding...^{xlix}

Residential service models can support community relationships by bringing the community to the facility. Such activities could include community gardens in the facility's grounds or children's music programs conducted within the facility. Within these settings the people with dementia as well as the community have the opportunity for mutual engagement. This recognises the importance of interdependence and reciprocity for people with dementia and highlights their retained social competencies and identities.

Advocacy

For dementia to be truly normalised, it needs to become an accepted, visible part of our society in the same way that physical disability is increasingly recognised as part of the norm^l

It has been argued by participants in our study and other research^{li lli} that only those who live with dementia can know what it is like. We need to ensure that the right of people with dementia to have their voices heard and understood is recognised. It is important for those involved in policy, advocacy, service delivery and research to accommodate the voice of carers and people living with dementia for better, more comprehensive and appropriate outcomes.

Conclusion

Participants in our study emphasised the importance of self advocacy. They suggested that people in the early stages of dementia could dispel the stereotypes that focus on late stage dementia and provide experiential learning for doctors, health professionals and community workers.

Indeed, in Australia there has been increased visibility and self-advocacy of people living with dementia from people such as Christine Bryden and the family of Hazel Hawke as well as the Shriver and Reagan families in the United States and the science fiction writer Terry Pratchett in the UK. When people living with dementia have the opportunity to tell their stories they offer real life examples of both the challenges and the opportunities that face people with dementia and also demonstrate that they have the ability and the right to active participation in society.

Community awareness

This paper has highlighted the need to reduce the fear and stigma attached to dementia. Community awareness and social marketing campaigns are one way of meeting that need.

Good social marketing can reduce the fear of dementia by portraying positive images of people living with dementia and at the same time be sensitive enough to enhance compassion and reduce blame. Effective public education provides positive, simple messages about dementia and corrects misinformation. But social marketing campaigns cannot work alone to reduce stigma. The availability of appropriate services, the advocacy of positive role models, the availability of dementia education programs for carers, health professionals and other workers all contribute to changing community attitudes and reducing the negative effects of stigma on the lives of people living with disease.

We have seen the effect stigma has on the lives of people with dementia, their carers and families. Stigma and discrimination erect barriers to service delivery, negate friendships and family relationships and diminish the self esteem and quality of life for people with dementia and their carers. Evidence of community attitudes about dementia and the level of understanding about the condition have also been documented. Key issues for discussion have emerged to enable a better understanding of this dilemma and see a way forward to enable all people living with dementia to engage more fully in a socially inclusive society.

Dementia is a terminal disease and currently there is no cure. This does not mean however that nothing can be done, that life with dementia is a hopeless scenario, or that people with dementia should be denied their civil and human right to participate in society. To ensure optimum social inclusion, the perceived stigma attached to dementia needs to be challenged. Increased community awareness and understanding of dementia is needed to alert policy makers, health professionals and the general public that all people living with dementia are a group of diverse individuals who should expect to be respected, cared for and supported; not because dementia has become a part of their lives but, because of their continuing place in our world.

Recommendations

1. The Australian Government, as part of the National Dementia Initiative, develop and fund an ongoing National Dementia Awareness Campaign that aims to increase an understanding of dementia to decrease stigma;
2. The Australian and NSW Governments fund social inclusion initiatives such as leisure and access programs that recognise the retained abilities of people with dementia and enable them and their carers to participate in mainstream community life;
3. The Australian Government amends aged care legislation to include enforceable quality dementia care standards, such as those developed by Alzheimer's Australia, which can be applied across aged care services. These standards should include staffing, ongoing training and appropriate workforce qualifications;
4. The Australian and NSW Governments fund programs for early diagnosis and timely referral to dementia support services to avoid the impact stigma has in delaying access to diagnosis and medical support;
5. The Australian and NSW Governments fund and support dementia-specific education and training for all personnel working in dementia care services to reduce prejudice and stereotyping amongst dementia-care workers;
6. The Australian Government recognise the need to invest in further social research into the effect of stigma on the lives of people living with dementia, their carers and families.

Endnotes

- i. UK Care Services Minister Phil Hope launching a campaign to raise awareness of living with dementia <http://newsvote.bbc.co.uk/mpapps/pagetools/print/news.bbc.co.uk/2hi/health> Downloaded 31/05/10
Access Economics (2010) Caring places: planning for aged care and dementia 2010-2050, Vol.1 Canberra
- ii. Milne, Alison, (2010) The 'D' word: reflections on the relationship between stigma, discrimination and dementia, *Journal of Mental Health*, June, 19(3)
- iii. Access Economics (2010) Caring places: planning for aged care and dementia 2010-2050, Vol.1 Canberra
- iv. Goffman, E. (1963) *Stigma: notes on the management of a spoiled identity*, Harmondsworth: Pelican
- v. Weiss, M., and Ramakrishna, J. (2006) Stigma interventions and research for international health, *Lancet* 2006;367:p.536
- vi. Burgener, S and Berger, B. (2008) Measuring perceived stigma in persons with progressive neurological disease: Alzheimer's dementia and Parkinson's disease, *Dementia*, vol. 7(1) 31-53
- vii. Attributed to Tom Kitwood in: Alzheimer's Society (2008) *Out of the Shadows*. London, Alzheimer's Society
- viii. Downs, M (2000) Dementia in a socio-cultural context: an idea whose time has come, *Ageing and Society* 20, 2000, 369-375, p.370
- ix. World Health Organisation (2003) *World Health Report 2003, Shaping the Future*, Geneva, World Health Organisation
- x. Milne, A., Woodford, H., Mason, J. and Hatzidimitriadou, E. (2000) Early diagnosis of dementia by GPs: an exploratory study of attitudes, *Ageing and Mental Health*. 4(4):292-300
- xi. Gilliard J, Means R, Beattie A, and Daker-White G. (2005) Dementia carer in England and the social model of disability, *Dementia: the international journal of social research and practice*, 4 (4): 571-586
- xii. The School of Nursing and Midwifery, Trinity College (2006) *Perceptions of Stigma in Dementia: an exploratory study*, 2006, Dublin, The Alzheimer Society of Ireland
- xiii. Innes, A., Archibald, C. and Murphy, C. (eds.), (2004) *Dementia and Social Inclusion: marginalised groups and marginalised areas of dementia research, care and practice*, London, Jessica Kingsley Publishers p.256
- xiv. Alzheimer's Australia (2010), *Dementia: evolution or revolution*, Alzheimer's Australia, Paper 19. Presented by Glenn Rees, Hammond Care 8th Biennial International Conference, June 2010
- xv. See Endnote v, xii, x, xv, xlii
- xvi. Alzheimer's Australia NSW Carer survey conducted by Policy and Information Unit, Sydney, Alzheimer's Australia NSW March 2010 for this discussion paper
- xvii. Alzheimer's Australia NSW Carer survey conducted by Policy and Information Unit, Sydney, Alzheimer's Australia NSW March 2010 for this discussion paper
- i. Nuffield Council on Bioethics (2009), *Dementia: ethical issues*, Cambridge, Cambridge Publishers www.nuffieldbioethics.org/fileLibrary/pdf/Dementia_Executive_Summary.pdf (downloaded 26/05/10)

- ii. Milne, Alison, (2010) The 'D' word: reflections on the relationship between stigma, discrimination and dementia, *Journal of Mental Health*, June, 19(3): p.228
- iii. Barnes, (2003); Cantley and Bowes, (2004). Cited in The School of Nursing and Midwifery, Trinity College, Perceptions of Stigma in Dementia: an exploratory study, 2006, Dublin, The Alzheimer Society of Ireland, p. 88
- i. Alzheimer's Society Canada, Brain Health Public Opinion Poll, Media Release, June 21 2007 <http://www.alzheimer.ca/english/media/headsup07-pollsummary.htm> (downloaded 30/5/10)
- i. Neuroscience Research Australia, Survey shows Australians worry about brain health, Media Release 31 May 2010 <http://www.neura.edu.au/news-events/news/survey-shows-australians-worry-about-brain-health> (downloaded 31/5/10)
- i. Bupa Care Services (2010), Bupa's 1st National Aged Care Consumer Survey, Sydney. www.bupacare.com.au (downloaded 06/08/10)
- i. Dementia Collaborative Research Centres and University of Newcastle, Assessment and Better Care Outcomes: focus group report. August 2007. [http://www.dementia.unsw.edu.au/DCRCweb.nsf/resources/Publications/\\$file/Pond_FocusGpReport.pdf](http://www.dementia.unsw.edu.au/DCRCweb.nsf/resources/Publications/$file/Pond_FocusGpReport.pdf) (downloaded 2/7/10)
- i. Dementia Collaborative Research Centres and University of Newcastle, Assessment and Better Care Outcomes: focus group report. August 2007. [http://www.dementia.unsw.edu.au/DCRCweb.nsf/resources/Publications/\\$file/Pond_FocusGpReport.pdf](http://www.dementia.unsw.edu.au/DCRCweb.nsf/resources/Publications/$file/Pond_FocusGpReport.pdf) (downloaded 2/7/10)
- ii. Goffman (1963) cited in Corrigan, P. and Miller F. (2004) Shame, blame and contamination: a review of the impact of mental illness stigma on family members, *Journal of Mental Health*, December 2004, 13(6): 537-548
- iii. Angermeyer, M. and Dietrich, S. (2006), Public beliefs about and attitudes towards people with mental illness: a review of population studies. *Acta Psychiatrica Scandinavica*. 113(3): 163-179
- iv. Burgener, S and Berger, B. (2008) Measuring perceived stigma in persons with progressive neurological disease: Alzheimer's dementia and Parkinson's disease, *Dementia* vol. 7(1) 31-53
- v. The School of Nursing and Midwifery, Trinity College (2006) Perceptions of Stigma in Dementia: an exploratory study, Dublin, The Alzheimer Society of Ireland. P.31
- i. Dementia Collaborative Research Centres and University of Newcastle, Assessment and Better Care Outcomes: focus group report. August 2007. [http://www.dementia.unsw.edu.au/DCRCweb.nsf/resources/Publications/\\$file/Pond_FocusGpReport.pdf](http://www.dementia.unsw.edu.au/DCRCweb.nsf/resources/Publications/$file/Pond_FocusGpReport.pdf) (downloaded 2/7/10)
- i. Dementia Collaborative Research Centres and University of Newcastle, Assessment and Better Care Outcomes: focus group report. August 2007. [http://www.dementia.unsw.edu.au/DCRCweb.nsf/resources/Publications/\\$file/Pond_FocusGpReport.pdf](http://www.dementia.unsw.edu.au/DCRCweb.nsf/resources/Publications/$file/Pond_FocusGpReport.pdf) (downloaded 2/7/10)
- ii. Myrra, J., Vernooij-Dassen, M. Moniz-Cook, E., Woods, R. De Lepelre, J., Leuschner, A., Zanetti, O., de Rotrou, J., Kenny, G., Franco, M., Peters, V. Illife, S. (2005) Factors affecting timely recognition and diagnosis of dementia across Europe: from awareness to stigma. *International Journal of Geriatric Psychiatry*, 20(4): 377-386
- i. Dementia Collaborative Research Centres and University of Newcastle, Assessment and Better Care Outcomes: focus group report. August 2007. [http://www.dementia.unsw.edu.au/DCRCweb.nsf/resources/Publications/\\$file/Pond_FocusGpReport.pdf](http://www.dementia.unsw.edu.au/DCRCweb.nsf/resources/Publications/$file/Pond_FocusGpReport.pdf) (downloaded 2/7/10)
- ii. Communication with Alzheimer's Australia NSW educator
- iii. Communication with Alzheimer's Australia NSW educator
- iv. Brown J. (2007) Quality Support Groups Research Project: a report on dementia support groups in New South Wales, Phase III, Alzheimer's Australia NSW, Sydney
- v. Low, Lee-Fay and Anstey, Kaarin (2009) Dementia literacy: recognition and beliefs on dementia of the Australian public, *Alzheimer's and Dementia* 5 p.47
- vi. Victor (2005) cited in Milne, Alison, The 'D' word: reflections on the relationship between stigma, discrimination and dementia, *Journal of Mental Health*, June 2010; 19(3): p.228
- vii. Milne, Alison (2010) The 'D' word: reflections on the relationship between stigma, discrimination and dementia, *Journal of Mental Health*, June; 19(3): p.229
- viii. The School of Nursing and Midwifery, Trinity College, Perceptions of Stigma in Dementia: an exploratory study, 2006, Dublin, The Alzheimer Society of Ireland. P.77
- ix. Mackenzie, J. (2006) Stigma and dementia: East European and South Asian family carers negotiating stigma in the UK, *Dementia* Vol 5 (2) 233-247
- x. Liu, D, Hinton, L., Tran, C., Dinton, D., Barker, J. (2008) Re-examining the relationships among dementia, stigma, and aging in immigrant Chinese and Vietnamese family caregivers, *Journal of Cross Cultural Gerontology* 23: 283-299
- xi. Innes, A., Archibald, C. and Murphy, C. (editors), (2004) *Dementia and Social Inclusion: marginalised groups and marginalised areas of dementia research, care and practice*, London, Jessica Kingsley Publishers p.171
- xii. Alzheimer's Society, (2008), *Out of the Shadows*. London, Alzheimer's Society p.56
- xiii. Hughes, Julian (2010) Ethical issues and decision-making in dementia care, Address to the National Press Club of Australia by Professor Julian Hughes, 22 June 2010
- xiv. Weiss, M., and Ramakrishna, J. (2006) Stigma interventions and research for international health, *Lancet* ;367:536-38
- xv. Scambler, Graham (2006) Sociology, social structure and health-related stigma, *Psychology, Health and Medicine*, August 2006; 11(3): 288-295
- xvi. Alzheimer's Australia (2009) *Dementia: facing the epidemic*. Compiled by Glenn Rees, CEO Alzheimer's Australia Canberra p.8
- i. Bird, M., MacPherson, S., Anderson, K., Davis, T. and Blair, A. (2008) Evaluation of the Art Gallery Access Programme for People with Dementia, Aged Care Evaluation Unit, NSW Southern Area Health Service, Canberra, Australian National University. www.nuffieldbioethics.org/fileLibrary/pdf/Dementia_Executive_Summary.pdf (downloaded 26/05/10)
- ii. Corrigan, P. and Miller F. (2004) Shame, blame and contamination: a review of the impact of mental illness stigma on family members, *Journal of Mental Health*, December 2004, 13(6): p.546
- iii. The School of Nursing and Midwifery, Trinity College (2006) Perceptions of Stigma in Dementia: an exploratory study, Dublin, The Alzheimer Society of Ireland

