

EXPLORING DEMENTIA AND STIGMA BELIEFS

**A PILOT STUDY OF AUSTRALIAN
ADULTS AGED 40 TO 65 YRS**

PAPER 28

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FOREWORD

In the last several years Alzheimer's Australia has commissioned work that has documented the economic and social impacts of dementia. We now know that approximately 280,000 people in Australia have dementia and more than one million people are caring for them. We also know that in surveys about health, dementia is rated by Australians as their second most feared disease after cancer.

Yet there is still little understanding of community attitudes towards people with dementia. We often hear from individuals with dementia and their family carers that after they received their diagnosis, friends and family stop calling and visiting, and invitations to social events stop coming. We also hear accounts of medical practitioners arguing the merits of treatment, saying "what's the point when they have dementia?" This report is the first attempt in Australia to quantify public attitudes about people living with dementia and to shed some light on the complexity of community attitudes.

The pilot study, which identified the views of 616 adults, found that some individuals have negative attitudes towards people with dementia. Half of the respondents believed that people with dementia cannot be expected to have a meaningful conversation and 34 per cent thought them to be irritating. More than one in ten indicated that they would avoid spending time with a person with dementia altogether.

But the story is not that simple. Many others who took part in the study felt that people with dementia should be included in social activities, and recognised their value and ability to participate.

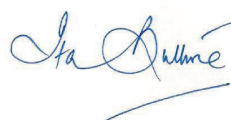
Perhaps most striking was the public expectation that if they received a diagnosis of dementia they would feel a sense of shame or humiliation, and would fear that their diagnosis would mean they would be discriminated against both in the community and the health sector. As a result, nearly a quarter of people indicated that they would delay seeking help for memory problems for as long as possible.

For those who would have the courage to seek help, 84 per cent indicated they would visit their GP if they thought they were experiencing early signs of the disease. This number highlights the importance of the GP and reinforces how critical it is for GPs to be properly trained to recognise the early signs of dementia so that they are able to refer people to a specialist for diagnosis when it is appropriate.

A diagnosis of dementia should not rob any Australian of the opportunity to engage in social activities and to pursue the quality of life they deserve. However, the community's lack of understanding about dementia and how best to respond to people who have the disease means this is not always the case.

We are a society in transition and have a long way to go before we can be confident that people with dementia will not be defined by their diagnosis.

Australia must continue to educate the general community and our health professionals in order to dispel the confusion surrounding dementia. Only then will we begin to see a shift in attitudes and reduce the stigma and social avoidance associated with this chronic disease.



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INTRODUCTION

Dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease but rather describes a degenerative neurological syndrome predominantly associated with ageing, which causes profound cognitive and functional disability, and eventually death (American Psychiatric Association, 1994). As the population in Australia continues to age, it is estimated that the number of people with dementia will increase from 280,000 in 2012 to almost a million by 2050 (Access Economics, 2009).

Over the past 5-10 years, partially due to acknowledgement of the ageing population and increased government funding for dementia research and care, the disease has had a higher profile in both public and scholarly discourse. This publicity may have increased public awareness of the syndrome, but some observers have noted that much of the associated discussion about dementia has focused on its 'most debilitating, demeaning and despairing features' (Jolley & Benbow, 2000, p. 117). Therefore, although public understanding of the seriousness of the syndrome may have improved, increased publicity could have contributed to public fear and a social construction of people with dementia that is potentially both prejudicial and dehumanising (Behuniak, 2011).

The term 'stigma' refers to the prejudicial views or negative stereotypes that individuals may hold about people with certain distinguishing characteristics or attributes (Byrne, 2001). This includes those living with particular health and medical conditions. Although stigma has not been studied extensively in the context of dementia, there is emerging evidence that dementia may indeed be a stigmatised condition. This requires further investigation because stigma and stigmatisation in other health conditions - including mental health, infectious diseases and disability (Harris, 1995) - have been associated with social exclusion of the stigmatised groups. In addition, stigma has been linked with discriminative practices within health care services, and delays in seeking diagnosis and treatment (Byrne, 2001; Parker & Aggleton, 2003).

DOES STIGMA EXIST IN RELATION TO DEMENTIA IN THE AUSTRALIAN COMMUNITY?

In Australia, there has been very little research to establish the extent or nature of stigma in relation to dementia. Our review of the literature indicates only three studies – all from the grey literature (e.g., technical, government reports etc that are not widely distributed or accessible) – that provide some insight into beliefs and attitudes about dementia that may be present in the Australian community (Alzheimer's Australia NSW, 2010; Low & Anstey, 2006; Stollznov Research, 2011).

This research has indicated that dementia is second only to cancer as the most feared condition in Australia (Alzheimer's Australia NSW, 2010; Stollznov Research, 2011). Carers of people with dementia from NSW have reported that they feel shame and embarrassment about the person they care for, as well as concern regarding the impact of stigma on their families (Alzheimer's Australia NSW, 2010). Many carers also believe there is a general lack of understanding regarding dementia in the Australian community (Alzheimer's Australia NSW, 2010). Indications of the presence of stigma were also supported in a national population survey which reported that 44% of people surveyed believed that people with dementia are discriminated against or treated unfairly, with 22% indicating that they would feel uncomfortable spending time with someone who had dementia (Stollznov Research, 2011). People with dementia and their families responding to the same survey reported experiencing social isolation, and 16% of the general public and 44% of carers indicated they knew someone who might have dementia but had not sought a diagnosis.

BACKGROUND TO THIS STUDY

Exploring the presence of stigma beliefs in a sample of Australian adults (40 to 65 years)

Existing research has provided some insight into the presence of stigma in relation to dementia. However, more research is needed to provide a more complete picture of the extent and nature of stigma associated with dementia in Australia. This paper presents a summary of results of an online survey with Australian adults in their middle years (40 to 65 years).

This target audience were chosen as they represent a sample of adults who may know someone with dementia (e.g. an ageing parent) and who, during the coming decades, may be faced with the need to proxy help-seek or help-seek if they themselves or a loved one experience symptoms of memory loss and confusion. The survey, explored the evidence for the presence of stigma in relation to dementia. Stigma is a complex construct, with several components. The specific focus for the study was to establish whether there was evidence in the sample of a desire for social exclusion or avoidance of people with dementia.

In addition, on the basis of consumer input from Alzheimer's Australia's Consumer Dementia Research Network (the Consumer Network), we also asked questions to assist in identifying evidence of attitudes that were positive. This was done in an attempt to contribute to a more balanced discourse around stigma that also acknowledges the potential for positive perceptions.

As a final objective of this research, we also examined whether stigma was associated with help-seeking intentions. This involved testing whether the elements of stigma assessed in this research predicted whether people would seek help for dementia if they noticed early signs of dementia. This is a critical area of research, given that early diagnosis of specific types of dementia, such as vascular dementia, can impact on prognosis.

METHODS

Measures of Stigma

We conducted a targeted but comprehensive literature search process to identify:

- (1) Effective ways of measuring 'separation' stigma toward people with dementia; and whether participants were conscious of stigma associated with dementia.
- (2) Existing valid and reliable tools/instruments to assess these categories of stigma in relation to dementia.

The literature indicated that stigma has been assessed in the context of many health conditions (e.g., depression, HIV/AIDS), along with ageing, but that few scales have been developed specifically to assess the domains of stigma in the context of dementia.

We identified one scale that assesses how participants would feel if they found out they had been diagnosed with dementia. This scale, the Perceptions Regarding Investigational Screening for Memory in Primary Care (PRISM-PC) - Dementia Screening Subscale (Boustani, et al., 2008), comprises 12 items reflecting possible responses to a diagnosis of dementia (e.g., "I would not want my family to know"; "I would feel humiliated"). Each item is assessed on a 5-point scale ('strongly agree' to 'strongly disagree'). This questionnaire was chosen for inclusion by the research team as a measure of stigma consciousness.

The Fraboni Scale of Ageism (Fraboni, Saltstone, & Hughes, 1990) was also identified as being relevant to explore the presence of 'separation' or avoidance beliefs in our context. This scale specifically addresses stigma and attitudes towards ageing, which we modified to assess attitudes towards people with dementia, rather than elderly people more generally. This was achieved by changing the words 'older people' to 'people with dementia'. All of the items were assessed on a 5-point scale ('strongly agree' to 'strongly disagree').

Finally, feedback from the Consumer Network indicated that it was important to examine whether people possess positive attitudes towards dementia and people with dementia (i.e., not solely negative or prejudicial views). However, we noted a lack of scales assessing positive attitudes or beliefs. Therefore, on the basis of existing scales for ageing, and in consultation with the Consumer Network, we developed ten additional items to assess more positive beliefs. These items consisted of statements such as "People with dementia are a good source of knowledge" and "People with dementia are respected for their wisdom," each of which was assessed on a 5-point scale ('strongly agree' to 'strongly disagree').

This process led to development of 31-items to assess the presence of select domains of stigma and person centred beliefs regarding dementia and people with the syndrome. In aggregate,

this scale assessed three fundamental areas of stigma: (1) whether Australian adults express a desire for separation or avoidance of individuals with dementia on the basis of their diagnosis; (2) whether some Australian adults also hold positive views towards people with dementia; and, (3) how Australian adults would respond if they found out they themselves had dementia. These items can be found in Appendix A.

Help Seeking Intentions

Studies examining the link between stigma and help-seeking intentions are limited. Bond, Stave et al. (2005) found that beliefs regarding treatment efficacy contributed to delays in seeking a diagnosis of Alzheimer's disease. Werner and Davidson (2004) also found that better knowledge of dementia symptoms was associated with increased intentions to seek help from professional sources such as a GP or neurologist. In this study, help-seeking intentions were evaluated on the basis of the Help Seeking Intentions scale (Wilson, Deane, Ciarrochi, & Rickwood, 2005) which asks participants to indicate the likelihood that they would seek help for a specific condition from a range of people including family members and health professionals. In the present study, we asked participants to indicate who they would seek help from if they were concerned they had early signs of dementia. A separate question required participants to indicate whether they would seek help on behalf of a partner or close family member if they felt that the individual was showing early signs of dementia (proxy help-seeking). In both instances, participants were also asked whether they would delay seeking help for as long as possible. For all items, participants responded on a 5-point scale ('extremely likely' to 'extremely unlikely'); a sixth response category (not applicable) was also included to allow for participants who may not have had a partner/parents etc. These items can be found in Appendix B.

Procedure

Participants completed an online questionnaire that incorporated the stigma and help-seeking intentions questions described above. Participants were recruited via a Facebook advertisement, National Seniors' newsletters, and Alzheimer's Australia emails and newsletters.

The online survey included questions on a range of relevant demographic characteristics. Participants were also asked whether they knew, or had previously known, someone with Alzheimer's disease or another type of dementia (e.g. a family member, friend, someone through work); and whether they had ever been a primary carer for someone with Alzheimer's disease or another type of dementia.

SUMMARY OF RESULTS

Demographics

The final sample consisted of 616 adults aged 40 – 65 years. Many participants were recruited via Facebook (40.3%), with a considerable proportion also recruited via National Seniors or Alzheimer’s Australia emails and newsletters (43.3%).

The vast majority of the people surveyed indicated that they knew someone with dementia (89.9%), and 21.8% were the primary carer of someone who had dementia.

Dementia beliefs – Inclusion or avoidance?

The responses to the dementia belief statements indicate the presence of negative beliefs regarding people with dementia, including a proportion of individuals who agreed (or strongly agreed) that people with dementia: cannot be expected to have a meaningful conversation (50.8%); can be irritating (34.0%); have poor personal hygiene (14.3%); and that they would avoid spending much time with a person who had dementia (11.7%).

Whilst these beliefs suggest that individuals hold some negative views of people with dementia, there was more evidence of a desire for social avoidance than broader social exclusion. This is evident in the comparatively lower agreement with statements such as ‘people with dementia don’t really need to use community facilities’ (1.4% agree or strongly agree) or that people with dementia should ‘live where they won’t bother anyone’ (1.3% agree or strongly agree).

Responses to the dementia belief items also highlight a considerable proportion of people who hold positive views about people with dementia. These included agreeing that: they are able to participate in a wide variety of activities (46.1%); their company is enjoyable (38.6%); they are a good source of wisdom (37.7%); and they can pass on valued traditions (34.4%).

Fear of dementia diagnosis and discrimination

The results for the Perceptions Regarding Investigational Screening for Memory in Primary Care (PRISM-PC) - Dementia Screening Subscale indicate that many individuals would have a negative response and anticipate stigma or discrimination if they were diagnosed with dementia. This included agreement (or strong agreement) that if diagnosed they would feel a sense of shame (60%) or humiliation (47%); and a strong negative affective response, which included anxiety (76%) and depression (70%). Responses also indicated that people felt a diagnosis may place them at risk of discrimination in the health sector.

Help-seeking Intentions

In terms of help-seeking intentions, most people indicated that they would seek help for themselves if they thought they were

experiencing early signs of dementia, most often from a GP (84%), or a partner (62%). Although only 8% of people indicated that they would not seek help from anyone, nearly a quarter (23%) indicated that they would delay seeking help for as long as possible.

In regards to proxy help-seeking, participants were more likely to report that they would seek help on behalf of someone else, and less likely to delay seeking help if they felt that the individual had early signs of dementia than they would if they themselves were experiencing the early signs. Whilst most still indicated they would seek help (on behalf of others) from a GP (81%), some sources of help varied significantly for proxy help-seeking (as opposed to help for self) with a higher intention to seek help from a phone helpline (54%), a parent (27%) or another relative (53%). Few individuals indicated that they would not seek help from anyone on behalf of another or that they would delay seeking help for as long as possible.

Dementia beliefs, stigma and help-seeking intentions

We examined whether help-seeking intentions (for self) were associated with responses to questions related to stigma and dementia. There was an association between the holding of particular beliefs and intentions to help-see. For example, individuals who indicated that they “would not want their family to know” or “would feel humiliated” if diagnosed with dementia were significantly more likely to indicate that they would seek help from no-one and would delay seeking help for as long as possible.

Higher scores on questions which dealt with fears of how doctors, health insurance or employers would respond to them receiving a diagnosis were also associated with an increased likelihood of seeking help from no-one and delaying seeking help for as long as possible.

Responses to questions on positive beliefs about people with dementia and responses to questions on social avoidance of people with dementia were not associated with help-seeking intentions.

DISCUSSION

The objective of this research was to investigate the presence of selected types of stigma in a community based sample of Australian adults.

Despite the majority of participants in this survey knowing someone with dementia, the findings suggest that the overall attitudes (and /or practices) of the sample of the Australian community towards people with dementia were sufficiently negative to lead to a stigma 'consciousness'. This is indicated by the high frequency of responses such as shame, humiliation and some fear by most surveyed in their response to the scenario about how they would feel if they themselves were diagnosed with dementia. This is significant because, while these questions do not directly measure the experience of discrimination, they may provide an indication of the extent to which people evaluate the potential consequences of the stigmatisation of dementia. This may be expressed as internalised shame and a fear of loss of power and respect in regards to treatment in the work and health sector.

Whilst there were those with a personal desire to avoid people with dementia, there was also a significant segment of the sample that held positive views about people with dementia. These views included recognition of their value, their capacity to participate, and their desire to live with some quality of life. Identification of such views in this sample may not be surprising due to the high number of carers and people who 'know someone with dementia'. However, identifying the presence of these beliefs is still important as such positive views have not been previously quantified in a community sample.

Of interest was the high proportion of participants who reported fear (or expectation) of direct discrimination in the health and employment sectors. This indicates a need for research to understand/document the experiences of people with dementia (and their carers) in relation to discrimination within each of these sectors, and what type of interventions may be required to address dementia related stigma in these sectors.

Results in regards to help-seeking intentions indicate that almost a quarter of this sample would delay seeking help for as long as possible if they felt they were showing early signs of dementia. In comparison, only about 10% of people indicated that they would delay seeking help on behalf of someone else who they felt had the early signs.

Those people who associated labelling or direct discrimination with dementia were less likely to seek help if they thought they were experiencing early signs of dementia, or that they would delay seeking help for as long as possible.

When help is intended to be sought, the vast majority of respondents indicated that they would seek help from a GP for themselves and on behalf of someone else. Unfortunately, GPs may not currently be well-equipped to act as the first point of call in dementia help-seeking,

with issues identified in relation to diagnosis (Pond, Mant, Kehoe, Hewitt, & Brodaty, 1994) and dissatisfaction with support that can be offered (Iliffe, Manthorpe, & Eden, 2003). Our findings reinforce the pressing need for GPs to receive more effective education and training to be better able to address the needs of people seeking help with memory loss and the symptoms of dementia.

Limitations and future research

To our knowledge, this is the first study to investigate stigma associated with dementia in a sample of Australian adults in their middle ages. There are, however, several limitations of the study that warrant discussion. First, this was a convenience sample recruited online and through seniors' organisations. It is unlikely that this is a representative sample and the results may be biased by the nature of the recruitment strategy. In particular, a considerable portion of the sample knew someone with dementia and more than one-fifth were or had previously been a carer for someone with dementia. It is possible that these factors could have influenced the pattern of responding on the stigma and person-centred scales; this may not reflect views of community members who do not have close contact with individuals living with dementia. A further consideration is that the majority of the sample was female. Thus, although the present results provide important insights into the types of stigma in an Australian context, the results require confirmation in a more representative sample.

The use of an ageing scale in this study prompts the need to explore the relationship between stigma and ageism and stigma and dementia, exploring those elements which may be distinctly associated with dementia as opposed to those labels and stereotypes that exist towards older people in general.

An additional limitation is that this study focused primarily on two types of stigma: Social Avoidance and Labelling. Link and Phelan (2001, 2006) also argue that stereotypes surrounding stigmatised conditions are also important, but these were not assessed in detail in the present report. In particular, issues associated with community labels or stereotypes that lead to a desire for social avoidance or rejection were not explored. Furthermore, there is a need to understand how stereotyping and labelling impact on fear of discrimination and/or actual discrimination within the health sector.

There is also a clear need for research to measure people's actual experience of stigma and stigmatisation (rather than just their beliefs about it) and, as such, research with carers and people with dementia is paramount to improve our understanding.

Finally, to improve the quality of life of people living with dementia and their caregivers, further work is required to understand how to address the labelling and stereotyping that may exist in relationship to dementia. In addition, further research should also explore how to best mediate or intervene to reduce stigma and discrimination in the community, and specifically in the health and employment sectors.

CONCLUSION

Understanding community attitudes to dementia is important, with this study highlighting the considerable impact stigma on the quality of life for people with dementia (and their carers) as well as the probable help seeking behaviours of people who may experience dementia in the future. There is a need for research to develop programs and strategies to reduce dementia related stigma and supporting timely diagnosis, effective treatment and maximising access to community based care to delay institutionalisation (AIHW, 2006).

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APPENDIX A

- 1. Complex and interesting conversation cannot be expected from most people with dementia**
 - 1 - Strongly Agree
 - 2 - Agree
 - 3 - Neither agree nor disagree
 - 4 - Disagree
 - 5 - Strongly Disagree
- 2. People with dementia are respected for their wisdom**
 - 1 - Strongly Agree
 - 2 - Agree
 - 3 - Neither agree nor disagree
 - 4 - Disagree
 - 5 - Strongly Disagree
- 3. Most people with dementia would be considered to have poor personal hygiene**
 - 1 - Strongly Agree
 - 2 - Agree
 - 3 - Neither agree nor disagree
 - 4 - Disagree
 - 5 - Strongly Disagree
- 4. Most people with dementia can be irritating because they tell the same stories over and over again**
 - 1 - Strongly Agree
 - 2 - Agree
 - 3 - Neither agree nor disagree
 - 4 - Disagree
 - 5 - Strongly Disagree
- 5. People with dementia live mostly independently**
 - 1 - Strongly Agree
 - 2 - Agree
 - 3 - Neither agree nor disagree
 - 4 - Disagree
 - 5 - Strongly Disagree
- 6. People with dementia don't really need to use our community facilities**
 - 1 - Strongly Agree
 - 2 - Agree
 - 3 - Neither agree nor disagree
 - 4 - Disagree
 - 5 - Strongly Disagree
- 7. It is best that people with dementia live where they won't bother anyone**
 - 1 - Strongly Agree
 - 2 - Agree
 - 3 - Neither agree nor disagree
 - 4 - Disagree
 - 5 - Strongly Disagree
- 8. The company of most people with dementia is quite enjoyable**
 - 1 - Strongly Agree
 - 2 - Agree
 - 3 - Neither agree nor disagree
 - 4 - Disagree
 - 5 - Strongly Disagree
- 9. I would try and avoid eye contact with someone if I thought they had dementia**
 - 1 - Strongly Agree
 - 2 - Agree
 - 3 - Neither agree nor disagree
 - 4 - Disagree
 - 5 - Strongly Disagree
- 10. People with dementia pass on valued traditions**
 - 1 - Strongly Agree
 - 2 - Agree
 - 3 - Neither agree nor disagree
 - 4 - Disagree
 - 5 - Strongly Disagree
- 11. I don't like when people with dementia try to make conversation with me**
 - 1 - Strongly Agree
 - 2 - Agree
 - 3 - Neither agree nor disagree
 - 4 - Disagree
 - 5 - Strongly Disagree
- 12. I personally would not like to spend much time with a person with dementia**
 - 1 - Strongly Agree
 - 2 - Agree
 - 3 - Neither agree nor disagree
 - 4 - Disagree
 - 5 - Strongly Disagree
- 13. People with dementia participate in a wide variety of activities and interests**
 - 1 - Strongly Agree
 - 2 - Agree
 - 3 - Neither agree nor disagree
 - 4 - Disagree
 - 5 - Strongly Disagree
- 14. People with dementia are a good source of knowledge**
 - 1 - Strongly Agree
 - 2 - Agree
 - 3 - Neither agree nor disagree
 - 4 - Disagree
 - 5 - Strongly Disagree
- 15. I would prefer not to go to a social group if people with dementia were also invited**
 - 1 - Strongly Agree
 - 2 - Agree
 - 3 - Neither agree nor disagree
 - 4 - Disagree
 - 5 - Strongly Disagree
- 16. People with dementia receive priority in care**
 - 1 - Strongly Agree
 - 2 - Agree
 - 3 - Neither agree nor disagree
 - 4 - Disagree
 - 5 - Strongly Disagree

17. I wouldn't bother visiting a person with dementia because they wouldn't remember that I came

- 1 - Strongly Agree
- 2 - Agree
- 3 - Neither agree nor disagree
- 4 - Disagree
- 5 - Strongly Disagree

18. People with dementia have care and concern for other people

- 1 - Strongly Agree
- 2 - Agree
- 3 - Neither agree nor disagree
- 4 - Disagree
- 5 - Strongly Disagree

19. There is no point in talking to someone with dementia because they can't take in what I say

- 1 - Strongly Agree
- 2 - Agree
- 3 - Neither agree nor disagree
- 4 - Disagree
- 5 - Strongly Disagree

20. If I had dementia I would not want my family to know

- 1 - Strongly Agree
- 2 - Agree
- 3 - Neither agree nor disagree
- 4 - Disagree
- 5 - Strongly Disagree

21. If I had dementia I would feel humiliated

- 1 - Strongly Agree
- 2 - Agree
- 3 - Neither agree nor disagree
- 4 - Disagree
- 5 - Strongly Disagree

22. If I had dementia I would no longer be taken seriously

- 1 - Strongly Agree
- 2 - Agree
- 3 - Neither agree nor disagree
- 4 - Disagree
- 5 - Strongly Disagree

23. If I had dementia I would be considered stupid and unable to do things

- 1 - Strongly Agree
- 2 - Agree
- 3 - Neither agree nor disagree
- 4 - Disagree
- 5 - Strongly Disagree

24. If I had dementia I would be ashamed or embarrassed

- 1 - Strongly Agree
- 2 - Agree
- 3 - Neither agree nor disagree
- 4 - Disagree
- 5 - Strongly Disagree

25. If I had dementia I would be depressed

- 1 - Strongly Agree
- 2 - Agree
- 3 - Neither agree nor disagree
- 4 - Disagree
- 5 - Strongly Disagree

26. If I had dementia I would be anxious

- 1 - Strongly Agree
- 2 - Agree
- 3 - Neither agree nor disagree
- 4 - Disagree
- 5 - Strongly Disagree

27. If I had dementia I would give up on life

- 1 - Strongly Agree
- 2 - Agree
- 3 - Neither agree nor disagree
- 4 - Disagree
- 5 - Strongly Disagree

28. If I had dementia my doctor would not provide the best care for my other medical problems

- 1 - Strongly Agree
- 2 - Agree
- 3 - Neither agree nor disagree
- 4 - Disagree
- 5 - Strongly Disagree

29. If I had dementia my doctor and other health professionals would not listen to me

- 1 - Strongly Agree
- 2 - Agree
- 3 - Neither agree nor disagree
- 4 - Disagree
- 5 - Strongly Disagree

30. If I had dementia I would not want my health insurance company to find out

- 1 - Strongly Agree
- 2 - Agree
- 3 - Neither agree nor disagree
- 4 - Disagree
- 5 - Strongly Disagree

31. If I had dementia I would not want my employer to find out

- 1 - Strongly Agree
- 2 - Agree
- 3 - Neither agree nor disagree
- 4 - Disagree
- 5 - Strongly Disagree

APPENDIX B

1. If YOU felt you were becoming more forgetful and were concerned it might be the signs of early dementia, how likely is it that you would seek help from the following people:

	Extremely Unlikely			Extremely Likely			Not applicable
Partner (e.g. husband, wife, significant other)	1	2	3	3	4	5	<input type="checkbox"/>
Friend (not related)	1	2	3	3	4	5	<input type="checkbox"/>
Parent	1	2	3	3	4	5	<input type="checkbox"/>
Other relative/family member	1	2	3	3	4	5	<input type="checkbox"/>
Counsellor, Psychologist or Psychiatrist	1	2	3	3	4	5	<input type="checkbox"/>
Phone Help Line (e.g. National Dementia Helpline)	1	2	3	3	4	5	<input type="checkbox"/>
Doctor/GP	1	2	3	3	4	5	<input type="checkbox"/>
I would not seek help from anyone	1	2	3	3	4	5	<input type="checkbox"/>
I would delay seeking help for as long as possible	1	2	3	3	4	5	<input type="checkbox"/>

If there others from whom you would seek help, please list them:

2. If you felt YOUR PARTNER or close FAMILY MEMBER was showing early signs of dementia, how likely is it that you would seek help ON BEHALF OF THEM from the following people:

	Extremely Unlikely			Extremely Likely			Not applicable
Partner (e.g. husband, wife, significant other)	1	2	3	3	4	5	<input type="checkbox"/>
Friend (not related)	1	2	3	3	4	5	<input type="checkbox"/>
Parent	1	2	3	3	4	5	<input type="checkbox"/>
Other relative/family member	1	2	3	3	4	5	<input type="checkbox"/>
Counsellor, Psychologist or Psychiatrist	1	2	3	3	4	5	<input type="checkbox"/>
Phone Help Line (e.g. National Dementia Helpline)	1	2	3	3	4	5	<input type="checkbox"/>
Doctor/GP	1	2	3	3	4	5	<input type="checkbox"/>
I would not seek help from anyone	1	2	3	3	4	5	<input type="checkbox"/>
I would delay seeking help for as long as possible	1	2	3	3	4	5	<input type="checkbox"/>

If there others from whom you would seek help, please list them:

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Papers

1. Dementia: A Major Health Problem for Australia. September 2001
2. Quality Dementia Care. February 2003
3. Dementia Care and the Built Environment. June 2004
4. Dementia Terminology Framework. December 2004
5. Legal Planning and Dementia. April 2005
6. Dementia: Can It Be Prevented? August 2005 (superceded by paper 13)
7. Palliative Care and Dementia. February 2006
8. Decision Making in Advance: Reducing Barriers and Improving Access to Advanced Directives for People with Dementia. May 2006
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18. Dementia: Facing the Epidemic. Presentation by Professor Constantine Lyketsos. September 2009
19. Dementia: Evolution or Revolution? Presentation by Glenn Rees. June 2010
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25. National Strategies to Address Dementia October 2011
26. Evaluation of NHMRC data on the funding of Dementia Research in Australia March 2012
27. Alzheimer's Organisations as agents of change April 2012

Reports commissioned from Access Economics

The Dementia Epidemic: Economic Impact and Positive Solutions for Australia. March 2003

Delaying the Onset of Alzheimer's Disease: Projections and Issues. August 2004

Dementia Estimates and Projections: Australian States and Territories. February 2005

Dementia in the Asia Pacific Region: The Epidemic is Here. September 2006

Dementia Prevalence and Incidence Among Australian's Who Do Not Speak English at Home. November 2006

Making choices: Future dementia care: projections, problems and preferences. April 2009

Keeping dementia front of mind: incidence and prevalence 2009-2050. August 2009

Caring places: planning for aged care and dementia 2010-2050. July 2010

Dementia Across Australia 2011-2050. September 2011

Other Papers

Dementia Research: A Vision for Australia. September 2004

National Consumer Summit on Dementia Communique. October 2005

Mind Your Mind: A Users Guide to Dementia Risk Reduction 2006

Beginning the Conversation: Addressing Dementia in Aboriginal and Torres Strait Islander Communities. November 2006

National Dementia Manifesto 2007-2010

In Our Own Words, Younger Onset Dementia. February 2009

National Consumer Summit Younger Onset Dementia Communique. February 2009

Dementia: Facing the Epidemic. A vision for a world class dementia care system. September 2009

These documents and others available on www.fightdementia.org.au

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