



# **Perceptions of Stigma in Dementia: An Exploratory Study**

*by*



**The School of Nursing and Midwifery  
Trinity College Dublin**

*August 2006*

## **Acknowledgements**

We would most sincerely like to thank the persons who participated in this study who included; a person with dementia, carers/family members, allied health professionals and representatives of disability organisations and the persons who acted as gatekeepers, without all of whom this study would not have been possible. This project was funded by the Alzheimer Society of Ireland, with part funding from the National Disability Authority's Research Promotion Scheme. In particular the research team would like to thank Ms Grainne McGettrick, Policy Officer with the Alzheimer Society of Ireland, for her help and assistance.

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# Executive Summary

## Introduction and background to the study

There are currently more than 33,000 people known to have dementia in Ireland. Due to its complex and multi-faceted nature, the impact of dementia on all those affected is extensive. Existing theories of stigma posit that possessing a disability such as dementia can result in a perception of difference between the person and others in the community, and potentially predispose the person with dementia to stigmatisation and discrimination. By association carers/family members of the person with dementia may also be subject to the effects of stigma or its components. It has been suggested that dementia related stigma is a concern in terms of the provision of dementia care and that it poses an obstacle to the well-being and quality of life of persons with dementia and their carers. To date this subject has not been explored in-depth from an Irish perspective. Consequently, the Alzheimer Society of Ireland commissioned this exploratory research, to better understand this issue and gain insight into how to respond to dementia related stigma in an Irish context.

## Aim and objectives of the study

The aim of the study was to conduct an exploratory study of stigma in dementia and the impact on all those affected, i.e. the person with dementia and his/her carers/family members.

The specific objectives were to:

- utilise grounded theory methods to gain an understanding of the concept of stigma in dementia
- examine the elements that lead to the construction of stigma in dementia and to understand their manifestation and application in day-to-day life
- explore the specific concepts of fear and discrimination associated with dementia as a disability
- identify potential strategies to deconstruct stigma associated with dementia.

## **Summary of the research methodology**

A qualitative exploratory approach using grounded theory methods guided the conduct of the study. The research included a critical review of the literature to identify the existing knowledge base relating to stigma and dementia related stigma. The study was granted ethical approval by the Ethics Committee of the Faculty of Health Sciences, Trinity College Dublin and in order to protect the potentially vulnerable populations interviewed, a multi-stage approach to ethical considerations was adopted. A total of 23 interviews were conducted with 24 participants from three groups: one joint interview with a person with dementia and carer, 12 interviews with carers/family members and 10 interviews with allied health professionals and disability organisation participants. Data were gathered using semi-structured non-directive interview guides which were piloted on three occasions. Data analysis procedures were consistent with those of grounded theory and the NVivo 7 (QSR International, 2006) computer analysis programme was used to facilitate the management of data and to record the research audit trail.

## **Summary of the findings**

The findings were integrated under nine themes and represent a preliminary exploration of stigma in dementia from the perspective of those interviewed.

- *Stigma and discrimination – is there or isn't there?*

Stigma or its components were referred to by the majority of participants and dementia related stigma was seen as having the potential to be damaging to those affected including carers/family members. For some participants the word stigma was not directly associated with dementia. When discrimination was described, it was related to structural or organisational discrimination, which participants felt was not intentional, but was instead about a failure to prioritise dementia in terms of policy and resource allocation.

- *“A dark secret still”*

Participants referred to the negative public images, stereotypes and terms associated with dementia, all of which could potentially lead to stigmatisation. Fear linked to dementia encouraged a reluctance to engage with those who have a dementia and avoidance was

highlighted as a common reaction to the presence of dementia. Importantly, this was an issue for health professionals too.

- *Behind the closed door – the reality of dementia*

Where experienced, stigma and its components were embedded in participants' overall experiences of dementia. The emotional impact was also significant. Examples of emotions relating to dementia related stigma included: anger and hurt due to diminished social networks and negative social encounters, embarrassment and shame if others became aware of dementia or witnessed inappropriate behaviours in public and carer/family member guilt where there was an inability to meet a perceived societal expectation to continue caring on an indefinite basis. It was suggested that dementia could either unify or divide a family, where there is an inability to accept dementia due in part to stigma related concerns.

- *Loss of place*

Participants from all groups referred to the potential for people with dementia to be treated inhumanely in society. There were references to perceptions of diminished value and negative interactions with people in society and service providers. Enforced social isolation was commonly experienced, due to withdrawal of friends etc. and barriers to social participation were outlined, resulting in social exclusion of the person with dementia and potentially the carer/family member. Carers described themselves as being at risk of similar experiences to the person with dementia and having to undergo a significant redefinition of life-space and role changes.

- *Navigating the system*

The complexity of interactions and experiences of the health and social care systems potentially contributes to dementia related stigma. While exemplars of excellence in care were frequently highlighted, there were references to structural difficulties and structural discrimination when journeying through the services available. Fragmented, inadequate or inflexible services which failed to offer choice or meet the needs of service users were described. Information provision was also cited as a significant issue.

- *Making safe – constant vigilance*

Carers/family members maintained a constant vigilance in terms of protecting the person with dementia. This protective role involves decisions as to when and to whom the diagnosis of dementia is disclosed, ensuring that the person with dementia is not exposed to the gaze of others or environments unsuitable to his/her needs, monitoring the nature and quality of services received, and protection of close others, for example, children from the reality of dementia including the risk of exposure to stigmatising experiences.

- *“Double whammy” – ageism and dementia*

Where people with dementia are older, it was suggested that ageist societal attitudes compounded the experience of dementia and that such people were at risk of being doubly stigmatised.

- *Viewing dementia as a disability*

Conceptualising dementia in terms of disability was advocated by a number of the allied health professional and disability organisation participants, as a positive step to advance measures to address dementia related stigma. It was also suggested that the focus should be on addressing components of stigma such as prejudice and discrimination.

- *The future – dementia ready*

Participants recommended numerous interventions targeted at personal, organisational and societal levels, with the intention of addressing dementia related stigma or its components. Regardless of the nature of these suggestions, the ultimate aim was the enhancement of the quality of life of the person with dementia and/or the carer/family member.

## **Recommendations**

### *Recommendations for policy*

- In terms of policy, dementia must be treated as a high priority policy issue. While An Action Plan for Dementia (O’Shea and O’Reilly, 1999) was devised, its

contents have yet to be fully implemented. More attention, more resources, and a real and lasting change in how dementia is conceptualised and approached by our society are all still needed.

- Specific health and social care policies are needed or must be revised to counter dementia related stigma.
- Greater levels of resources are needed to augment the availability, accessibility and usefulness of person-centred dementia specific services that support the abilities of people with dementia.
- Current services must be reviewed and the system fragmentation and lack of communication reported by participants addressed, with the intention to create a seamless system.
- New ways are needed to ensure that the citizenship and social inclusion of people with dementia and their carers/family members are respected and ensured.
- People with dementia must be involved with policy planning and development.
- There is a need to further develop a robust advocacy movement to lobby for and with people with dementia and carers/family members.

The Alzheimer Society of Ireland, National Council on Ageing and Older Persons, The National Disability Authority and other interested agencies and organisations involved in planning and advocating for policy changes have important roles in ensuring that these issues are raised and addressed in appropriate policy arenas. However, more immediate change in the way services are delivered is possible; the Department of Health and Children and the Health Services Executive and other relevant state agencies may rely on the mandates of existing policy documents, such as An Action Plan for Dementia (O'Shea and O'Reilly, 1999), Sustaining Progress: Social Partnership Agreement. 2003-2005 (Department of the Taoiseach, 2003), Quality and Fairness; A Health System for You (Department of Health and Children, 2004) and Towards Best Practice in Provision of Health Services for People with Disabilities in Ireland (Pillinger, 2004).

### *Recommendations for service planning*

- A priority should be the establishment of a core of community based case managers, involved from the time of diagnosis throughout the dementia

continuum, as a resource for people with dementia and/or their carers/family members.

- A package of person-centred flexible services which can change to suit the needs of an individual as a dementia progresses including; services designed to meet the needs of younger people with dementia, services that can be offered at diagnosis and through each stage of dementia, and services that meet out of hours, weekend and twilight needs.
- The involvement of people with dementia and/or their carers/family members when devising personal care plans, to ensure that service provision meets their identified needs and wants.

These recommendations respond to the direct daily challenges for people with dementia and their carers/family members. Some policy changes may be needed to support their implementation, but it is likely that solutions already lie within the remit of Department of Health and Children and the Health Services Executive and with physicians and other health and social care professionals, changing care practices to ensure inclusivity of people with dementia and their carers/family members and to recognise and uphold the continuing abilities of people with dementia. Advocacy by people with dementia themselves, carers/family members, the Alzheimer Society of Ireland, National Council on Ageing and Older Persons, The National Disability Authority and others will also be required, to ensure that concrete steps are taken to implement such recommendations.

#### *Recommendations for information provision and education*

- Dementia specific education is recommended for health, social care, legal and environmental planning professionals.
- Education programmes must convince recipients of the importance of stigma, challenge stereotypes and offer strategies to address the components of stigma including prejudice and discrimination.
- Existing media awareness campaigns should be continued, collaboration with the media should be expanded and specific efforts undertaken to illuminate and challenge the components of stigma in dementia.

Media outlets and educational institutions are already doing a lot in respect to these recommendations and their contributions are acknowledged, as is the fact that they have other pressing public information and training priorities to address. However, this study clearly illustrates that people with dementia and their carers need more information and better informed providers. Each professional area working with people with dementia and each institution in Ireland preparing such professionals, must commit to addressing stigma and challenging stereotypes. Changing the views of society and professionals about dementia will further require the sustained support of the Alzheimer Society of Ireland, the media, the Dementia Services Information and Development Centre the National Council on Ageing and Older Persons, The National Disability Authority, and other interested organisations.

### **Implications for further research: setting the research agenda**

- The impact of stigma or its components on dementia policy and on the practice of professional care requires further exploration, particularly the influence of discrimination, prejudice and stereotyping.
- There is scope to create a theory which outlines how the components of dementia related stigma impact on the relationship between those affected by dementia and health and social care professionals. Such theory development may then help guide the development of education and intervention programs designed to address and contain stigma related concerns.
- Where service providers have personal experience of dementia, there is the potential to explore the effect on professional perspectives and how this might impact on relationships between service providers and carers and people with dementia.
- Research is needed to support the design, implementation and evaluation of regional integrated approaches to services and on how policy, training and media approaches may impact upon dementia related stigma, including changes in dementia knowledge, attitudes and behaviours.
- Research that investigates the nature of relationships between those with dementia and those around them, family, neighbours, the local community, may help

illuminate how stigma and its components affect social interaction and constructs such as social distance.

The research funding priorities of the Health Research Board, the National Disability Authority, the National Council on Ageing and Older persons and of other public and private funders, should include the addressing of stigma related issues and the development of more responsive evidence based service approaches. Existing research groups should also develop the needed research designs and expertise to support these priorities.

# Chapter 1 – Introduction

## 1.1 Background and context

Recent estimates have suggested that there are currently 24.3 million people with dementia in the world and that this figure is set to double every twenty years to reach 81.1 million people by 2040 (Ferri et al., 2005). In Ireland, there are approximately 33,000 persons with dementia, with predicted increases estimated at 66,610 persons by the year 2026 (Central Statistics Office, 2004). Dementia is characterised by impaired memory, impaired ability to learn, impaired ability to reason and high levels of stress (Marshall, 1997). The impact of dementia on those affected is clearly extensive, as the effects permeate all aspects of the person's life. However, little is known about the experience of having dementia from the perspective of the person with dementia (Aggarwal et al., 2003). In addition the majority of persons with dementia reside in the community and are cared for by family members. As there is no Irish database of people with dementia, it can be difficult to access and estimate the number of family caregivers and consequently understand their experiences. However, an Irish study by O'Shea (2003), which explored the costs and consequences for carers of people with dementia, highlighted the constant and progressive nature of care-giving, worrying levels of strain and psychological distress, as well as the significant economic costs of caring.

Possessing a chronic illness or disability such as dementia, can result in a perception that an individual differs from the general population and could subject a person to possible stigmatisation and discrimination by others who do not have the illness (Joachim and Acorn, 2000). Stigma has been defined as a sign of disgrace or discredit that is considered to be undesirable by society (Goffman, 1963; Jones et al., 1984), defines the person who possesses it and sets him/her apart from another (Miles, 1981; Byrne, 2001). As such stigma can affect the identity of an individual and importantly his/her carers/family members (Ablon, 2002). According to the United States Department of Health and Human Services (1999: 6), stigma “deprives people of their dignity and interferes with their full participation in society”. It is suggested that dementia related

stigma is a concern in dementia care provision and an obstacle to well-being and quality of life (Sartorius, 1998; Reidpath et al., 2005). For example stigma has been shown to influence delays in dementia recognition and diagnosis in primary care, as a result of the person with dementia, family members and others concealing, minimising or ignoring early signs and symptoms (Myrra et al., 2005).

## **1.2 What is dementia?**

Historically, dementia was understood solely as a disease (Clare, 2002; Hellstrom et al., 2005) and was the concern of disciplines such as pathology, genetics and medicine. Such an emphasis led health professionals to think of dementia in terms of an illness characterised by losses. Medicalising dementia in turn led to a search for treatments and cure, while less consideration was given to the everyday care of people with dementia or to care-giving relationships and contexts (Bond, 2001). Society tended to perceive people with dementia as less than human, which might have resulted in actions that caused depersonalisation, disempowerment and loss of self-worth and self-esteem (Kitwood, 1997). Traditional explanations which situated dementia solely within the domain of orthodox medicine (Harding and Palfrey, 1997) are however insufficient, due to the assumption of a straightforward linear relationship between brain pathology and dementia (Kitwood, 1993; Veyard, 2001). As dementia refers to a number of illness it is better understood as an umbrella term.<sup>1</sup> Many writers conceptualise dementia as a disability that results from multiple factors, including neurological and social-psychological ones (Kitwood, 1990; 1993; Goldsmith, 1986). Such perspectives have resulted in what is described as the new culture of dementia care. This approach emphasises the humanity of the person with dementia and the imperative to promote his/her personhood (Kitwood and Benson, 1995).

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<sup>1</sup> Some of the more common forms of dementia include: Alzheimer's disease, vascular dementia, Lewy-body dementia and mixed type dementias. Other types of dementia include fronto-temporal dementia, Creutzfeldt-Jakob disease, Huntingdon's disease, alcoholic dementia and AIDS-related dementia. The causes of dementia are in the main still unknown although genetic and environmental causes have been demonstrated in some cases.

### **1.3 Dementia as a disability**

The recent Disability Act (Government of Ireland, 2005:6) defines disability as “a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment”. This supports Priestly’s (2003) earlier description of disability as four intersecting circles of experience: the body, identity, culture and structure. Disability experience is therefore suggested to be both a personal and a global phenomenon with economic, cultural and political ramifications (Barnes, 2002). Dementia is identified as a major cause of disability and one of the most serious challenges currently facing health and social care services (Milne et al., 2000). Global burden of disease estimates, from the World Health Report 2003 (World Health Organisation, 2003), suggest that dementia contributed 11.2 % of years lived with disability in persons over 60 years, which is more than stroke (9.5%) or cardiovascular disease (5.0%). Iliffe et al. (2005) suggest that thinking about dementia as a slowly evolving disability is helpful because it has the potential to improve communication and to reduce anxiety for all those affected. Viewing dementia as a disability emphasises its bio-psycho-social and environmental components, respects the personhood of the person with a dementia and encourages a focus on the person’s retained abilities in contrast to losses.

### **1.4 Irish dementia policy**

In An Action Plan for Dementia, O’Shea and O’Reilly (1999) provided direction for the development of Irish dementia policy and service provision. According to this document, the complex nature of dementia and range of related issues highlight the need for “co-ordinated, multi-layered and well resourced services responsive to the individual needs of people with dementia and their carers” (O’Shea and O’Reilly, 1999:6). Despite this however, much is still to be done in relation to improving the experience of dementia for the person with dementia and carers/family members. Quin and Redmond (1999) in relation to Irish disability social policy, write that while awareness of disability has grown among the public, understanding of the experiences of those with disability and

those who care for them has not matched this awareness. The person with dementia is subjected to a double edged sword i.e. living with dementia and the potentially negative attitudes and behaviours of others. Anecdotal reports indicate that many people with dementia and their carers/family members are at risk of experiencing various forms of stigma. As such the need to address dementia related stigma has been highlighted as one of the key objectives in the Alzheimer Society of Ireland's new three-year strategic plan. To contribute to the debate surrounding the subject of stigma and dementia, the Alzheimer Society of Ireland therefore funded and independently commissioned this research in order to better understand and gain insight into how to respond to this complex area.

### **1.5 Rationale for the current study**

To date little is known from an Irish perspective about the personal experiences of people with dementia and the experience of their carers/family members in relation to dementia and perceptions or experiences of dementia related stigma. The purpose of the research reported here was to conduct a qualitative exploratory study to understand this phenomenon from a range of perspectives, as understanding the perspective of those affected is crucial prior to the development of interventions. Thus, in order to address the research purpose, a person with dementia, carers/family members and a range of allied health professionals and disability organisation participants were interviewed.

## Chapter 2 - Literature Review

### 2.1 Introduction

This literature review<sup>2</sup> presents an overview of the existing knowledge base relating to stigma. While, the volume of literature relating specifically to stigma and dementia is more limited, the number of citations referring to stigma and conditions to which stigma has been applied is voluminous. Having tentatively explored the wider stigma literature, the literature relating to persons with mental health problems and marginalised groups with disabilities, including persons with intellectual disability, was found to be particularly relevant. Consequently this literature, the stigma related dementia specific literature and relevant studies from the wider stigma literature will primarily feature in this review.

### 2.2 What is stigma?

The term stigma originated in Greece, referring to a tattoo or mark branded on a person to demonstrate devotion to the religious services of the temple. Later stigma became linked to the marking of a person as a slave or criminal and then to bodily signs illustrating something unusual or negative about the moral status of a person. Currently stigma is applied to a continually widening circle of contexts (Prior et al., 2003) and defined in a number of ways (see Table 2.1 below):

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<sup>2</sup>The literature in this review was sourced via manual searches of bibliographic indexes and computerised searches of databases including: the Cumulative Index of Nursing and Allied Health Literature, EMBASE.com, IngentaConnect, Ireland and Northern Ireland's Population Health Observatory, Medline, Pubmed and PSYCHLIT. Keywords used to locate pertinent literature included: dementia, Alzheimer's, stigma, disability, family, carers, health professionals and various combinations of these. Relevant policy documents were also consulted. This strategy identified a wide range of original research, review and opinion papers representing a varied geographic spread. A paucity of Irish research was found strengthening the need for the current study.

**Table 2.1 Definitions of stigma**

- A “special kind of relationship between attribute and stereotype ... attribute that is deeply discrediting .... Reduces the bearer ... from a whole and usual person to a tainted, discounted one ... We believe that a person with a stigma is not quite human ...” (Goffman, 1963: 14-16)
- “a societal reaction which singles out certain attributes, evaluates them as undesirable and devalues the persons who possess them” (Miles, 1981: 70)
- “bearer of a “mark” that defines him or her as deviant, flawed, limited, spoiled or generally undesirable ... To stigmatise a person generally carries a further implication that the mark has been linked by an attributional process to dispositions that discredit the bearer, i.e. that “spoil” his identity” (Jones et al., 1984: 6,8)
- “some attribute or characteristic, that conveys a social identity that is devalued in a particular social context” (Crocker, Major and Steele, 1998: 505)
- “ a sign of disgrace or discredit which sets a person apart from others” (Byrne, 2000: 65)
- “the co-occurrence of its components - labelling, stereotyping, separation, status loss and discrimination – and further indicate that for stigmatization to occur, power must be exercised” (Link and Phelan, 2001: 363)

Goffman (1963) proposed three types of stigma:

- Physical stigma associated with deformity of the physical body,
- Conduct stigma associated with character blemishes and
- Tribal stigma passed through lineages and applied to members of a family.

According to Goffman (1963) society has stereotypical expectations relating to how a person ought to be, known as a virtual social identity<sup>3</sup>. A person’s actual social identity may differ as attributes possessed may not match the expected stereotype. The

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<sup>3</sup> A stereotype is a form of social typing, which has the potential to be misleading, as it does not acknowledge variability (Rogers and Pilgrim, 2005).

discrepancy between the two identities generates stigma (Porter, 1998). Stereotyping consequently causes stigmatisation when prejudicial social typing occurs accompanied by features such as avoidance, pity or revulsion (Rogers and Pilgrim, 2005). Illnesses which are highly visible and intrusive are particularly subject to stigma (Scambler, 1998). It has been suggested that stigma is more typically attached to an illness for which the person is considered responsible (Albrecht, Walker and Levy, 1982) and also to conditions of the mind - such as dementia. Stigma is consequently understood as something in the person and not attached to the individual (Link and Phelan, 2001). This is despite Goffman's (1963) emphasis on stigma experiences residing in the interaction between persons perceived as 'different' and 'normals', who interpret the difference as negative.

In contrast Halter (2000) promotes an interactive perspective of stigma, as a self and societal perception of shame or flaw, which is intransigent and internalised. The elements or dimensions of stigma have been outlined by Jones et al. (1994) (appendix 1). Stigma is associated with inferior attributes regarded as infractions of major societal norms (Page, 1984). This suggests that stigma is linked to cultural and societal values where an attribute can convey a social identity that is not valued in a social context (Crocker et al., 1998; Whitehead et al., 2001). Current definitions, such as Link and Phelan's (2001) above, increasingly define stigma in terms of processes and not descriptions of signs and have the advantage of enabling the systematic investigation of the relationship between the components of stigma (Prior et al., 2003; Angermeyer and Dietrich, 2005). Link et al. (2004) have further advanced their definition with the addition of emotional reactions. Stigmatisation is viewed as complete when various forms of disapproval, disempowerment, rejection, exclusion and discrimination are applied (Link, 2000).

### **2.3 Difficulties with defining stigma**

- Despite a multitude of definitions stigma as a concept remains imprecise and somewhat elusive (Page, 1984). Due to its historical and cultural nature, what constitutes stigma is related to public perceptions and a norm in a one historical period may alter (Joachim and Acorn, 2000).

- When defining stigma, a variety of terms are employed, e.g. social stigma (Jones et al., 1984; Crocker, 1999), self-stigma, public stigma (Corrigan and Penn, 1999; Knight, Wykes and Hayward, 2003), direct and indirect stigma (Wahl, 1999), felt and enacted stigma (Green et al., 2005) and stigma is linked to multiple issues (e.g. mental illness, intellectual disability, crime, epilepsy, obesity, cancer and HIV). Consequently stigma can be understood in unique or different ways.
- The study of stigma is also multidisciplinary and while there is shared interest among researchers, there is also a difference in emphasis (Link and Phelan, 2001), both within and between disciplines.
- While traditionally the concept of stigma may have been absolute, analysis from post-modern perspectives challenges society with the variability of existing concepts of stigma (Scambler, 1998). A universal definition of stigma may not therefore be possible. There is a consequent need to understand the nature and experience of stigma, from the perspective of those who experience it and within the social contexts in which it occurs.

#### **2.4 Being stigmatised - responses to stigmatisation**

Stigma involves attitudes, feelings and behaviours (Morgan et al., 2002). When faced with stigma, people can respond in a variety of ways. Within intellectual disability, social comparison is frequently explored in relation to stigma and identity. Jahoda, Cattermole and Markova (1988) explored the experience of living with intellectual disability (n=20) and found that participants were stigma aware and managed this in two ways. They distanced themselves from the label by describing themselves in terms of people without an intellectual disability or they highlighted the differences between themselves and others with a more severe intellectual disability. Such downward comparisons may serve as a strategy to preserve self-esteem (Dagnan and Sandhu, 1999). Similar findings have been shown by Gibbons (1985), Craig et al. (2002) and Cooney et al. (2006). Rapley, Kiernan and Antaki (1998) found that participants attempted to become invisible and pass for normal. The person with an intellectual disability may therefore deal with difference by denying its existence (Stokes and Sinason, 1992).

Goffman (1963) and Link, Mirotznik and Cullen (1991) identified three stigma coping methods – avoidance-withdrawal, education and secrecy. Link, Mirotznik and Cullen (1991) demonstrated that applying these mechanisms tended to produce harm and not good. For example with the onset of symptoms, the effects of discrimination and stigma can negatively impact on contact with health services. A European study with a multi-disciplinary expert group supports this. The study explored the obstacles to the recognition of and response to dementia (Iliffe et al., 2005). The ‘patient journey’ was found to be shaped by ageism and stigma. Early changes of dementia were minimised or attributed to normal ageing and accommodated by the person and their carers/family. While this could be interpreted as a coping strategy, it could also delay diagnosis and service access. Morgan et al. (2002) in a Canadian descriptive qualitative study with home care staff and family members also found that stigma associated with dementia directly impacted on service use. Social embarrassment resulted in people isolating themselves. While, denial, pretence and covering up for behaviours can be a means of protection, they could lead to reduced supports, as help may not be sought or offered.

Persons who perceive themselves as stigmatised may internalise stigmatising ideas (Graham et al., 2003). In relation to lung cancer, Chapple, Ziebland and McPherson (2004) found participants felt that they could be blamed for their illness because of its links with smoking and some smokers feared they could even be denied treatment. Shame has been shown to outweigh the symptoms of a stigmatising mental illness and secrecy is identified as the adaptive response to shame (Byrne, 2000). However, secrecy does not reduce fear of discovery, a finding supported by Wahl (1999) in an American nationwide survey of 1301 mental health consumers’ experiences of stigma and discrimination. Emotional responses to stigma in this study also included anger, hurt and discouragement. As part of a Mid Western United States metropolitan area study on quality of life in persons with early stage dementia, Katsuno (2005) explored the impact of negative public attitudes towards the disability. Participants reported being devalued and treated as if they did not exist. Hurt and fear were expressed. Specifically fear was described in relation to the ‘disease’, fear of devaluation, mistreatment, isolation and loss

of friends. Participants responded by trying to conceal the symptoms such as memory loss.

Information control in social interaction with the outside world has also been explored in persons with cancer (e.g. Rosman, 2004). Such research supports Goffman's (1963) theory that persons attempt to conceal stigma in two ways – *passing* (concealing information so that the stigma is not noticeable in daily life) and *covering* (active attempts to minimise obtrusiveness when the stigma is becoming visible or is known about). Concealment is influenced by the visibility of the stigma and evaluation of whether it will influence social encounters. In relation to Alzheimer's disease, Blum (1991) critiques this perspective, suggesting it is an assumption that the person possessing the stigma is the primary person controlling its management. Where the person lacks the capacity to manage discrediting or discreditable information, it is the carer/family member who becomes what Blum (1991:264) terms the 'team leader'.

## **2.5 Consequences of stigmatisation**

Reidpath et al. (2005) outline four ways in which stigma may affect health – firstly stigma can negatively impact on the health of the person who is stigmatised, secondly fear of stigma and discrimination may result in self-regulated exclusion, thirdly persons may experience stigma even though they may not expect it (e.g. poor quality services) and finally stigmatising one group may negatively affect the health of a broader population. It can thus be argued that the effects of stigma have internal and external consequences.

### *2.5.1 Internal consequences*

Link and Phelan (2001) contend that the impact of stigma is immeasurable affecting multiple domains of peoples' lives including quality of life and psychological and social well-being. Dinos et al. (2004: 176) in a British study found that while concealment of an illness may not be feasible, managing information concerning a stigmatising illness is a "potent source of stress, anxiety and further stigma". In relation to those with mental health issues, this is linked to experienced and anticipated discrimination (Alexander and

Link, 2003). Stress has also been associated with the continuous threat of being stigmatised which can increase a person's risk of acquiring other stress related illnesses (Link and Phelan, 2006). Corrigan et al. (2005a) suggest three further overall effects of stigma on the individual. Firstly 'label avoidance' (a recurrent theme throughout the literature) where to avoid labelling the person may not access the services to which they are entitled. This is internally imposed stigma where a person behaves in ways designed to avoid stigmatisation by others (Last, 2000). Secondly 'blocked life goals', due to the prejudices of others, it may be difficult to pursue employment or access to services. Thirdly 'self-stigma' may result in a lowering of self-esteem and self-efficacy (Wahl, 1999; Byrne, 2001; Link and Phelan, 2001). For example Knight, Wykes and Hayward (2003) in their phenomenological study of stigma in schizophrenia found that diagnosis had an extensive effect on self-concept and daily experiences.

### *2.5.2 External consequences*

Stigma causes distress, reduced acceptance, discrimination and rejection (Huxley, 1993; Alexander and Link, 2003; Angermeyer, Schulze and Dietrich, 2003). According to Last (2000), social exclusion and discrimination are endpoints of stigmatisation. Stigma is therefore a public health problem and a social justice issue (Corrigan et al., 2005a). People with disabilities often find themselves in a liminal state, as they don't fit within traditional categorisations (Murphy et al., 1988). Others may not be sure how to treat the person and social awkwardness occurs, reducing quality and quantity of social interaction. Avoidance by other people including family, friends, co-workers and community members is linked to the awareness and visibility of a stigma related illness or disability (e.g. Chapple, Ziebland and McPherson, 2004; Rosman, 2004; Wilson and Luker, 2004). Awkwardness is also a recurrent theme in the stigma literature. For example, Green et al. (2005) found awkwardness in a study of persons and their families with a number of disabilities (including persons with hearing impairments, wheelchair users and life-long physical impairment). From an Irish perspective Mulrooney and Harrold (2004) found that when informed that their child had an intellectual disability,

parents reported their sense of isolation and non-parent participants spoke about feelings of awkwardness.

Link and Phelan (2001) suggest where there is labelling, stereotyping and separation, acts can be perpetrated which might limit the social participation of persons who are stigmatised. Social exclusion exists when groups are unable to achieve normal levels of social acceptance and participation e.g. “accepted levels of material well-being and social benefits and a positive estimation of social status and identity” (Burden and Hamm, 2000: 184). The recent Vision for Change report suggests that “people with mental health problems are particularly vulnerable to social exclusion” (Department of Health and Children, 2006: 34). Social exclusion can negatively impact on the health and well-being of the excluded (Reidpath et al., 2005). Other external consequences include: ageism, prejudice and stereotypes, which can lead to discrimination (Graham et al., 2003). As the majority of people with dementia are older, this is significant as Bythway (1995) equates ageism with social oppression.

Oppression is linked to the exercise of power and Link and Phelan (2001) suggest that power is necessary for stigmatisation. This is not to neglect the experience of younger persons with dementia who have many of the same experiences as older people with dementia and some more unique. (See Haase (2005) in relation to early onset dementia in an Irish context). Stigmatised persons may specifically be at risk of structural discrimination whereby stigma affects “the structure around the person, leading the person to be exposed to a host of untoward circumstances” (Link and Phelan, 2001:373). Structural discrimination is underpinned by socio-political factors and evidenced in institutional policies and practices which can disadvantage stigmatised groups, even when discrimination against the individual is absent (Link et al., 2004; Corrigan et al., 2005b). In terms of disability discrimination, the outcomes may include: marginalisation within health systems, inadequate service funding at national and local level, avoidance, social distance, isolation and lack of knowledge about the experiences of those who are the subject of stigma.

## **2.6 The carer/family member experience**

According to Goffman (1963) stigma is also felt by close carers/family members and others. This is described within the literature as ‘courtesy stigma’ or ‘stigma by association’ and there is a growing body of research, which outlines the process, experience and strategies used to manage such stigma.

### *2.6.1 The experience of courtesy stigma/stigma by association*

Those subject to courtesy stigma, in common with the person with the stigma, are at risk of increased emotional effects and social isolation (e.g. Blum, 1994; MacRae, 1999; Struening et al., 2001; Angermeyer, Schulze and Dietrich, 2003; Green et al., 2005; Chang and Horrocks, 2006). Ostman and Kjellin (2002), in a Swedish multi-centre study, measured burden and need for support in 162 relatives of persons with mental illness. Eighty-three percent reported burden in one or more of the measured psychological factors of stigma by association. A high proportion of relatives reported that the illness had affected the possibility of having company and relations with others and had led to mental health problems for themselves. Carer support was derived from other family members and close friends and less frequently from health services. Indeed some relatives reported feeling inferior when conversing with healthcare staff.

Similar findings have also been reported by Angermeyer, Schulze and Dietrich (2003) in a German study of 122 relatives of persons with Schizophrenia. Four domains of stigma were described, three of which pertained to relatives experiences. The first domain interpersonal interaction referred to stigma experienced in social relationships. Participants felt stigmatised by health professionals who spoke down to them and did not acknowledge their competence and experience as carers (also demonstrated by Gillman, Heyman and Swain (2000)). They also felt socially excluded, as friends and relatives withdrew and guilty and helpless when sometimes blamed for the illness. Assignations of blame for the actions of those possessing a stigmatising attribute have also been found by Green et al. (2005). The second domain identified was structural discrimination in which negative consequences resulted from imbalance and injustice in social structures, political decisions and legal regulations. Relatives felt that the health care system was confusing

and bureaucratic and they experienced financial burden and a lack of crisis supports. In the domain of public images of mental illness, relatives described the stereotypes portrayed in the media and ignorance and lack of information. They also highlighted the unequal status of somatic and mental illness.

### *2.6.2 The management of courtesy stigma/stigma by association*

Blum (1991) engaged in participant observation in a support group for family carers of persons with Alzheimer's disease and conducted in-depth interviews with 34 caregivers over a period of three years. In her findings, she described two phases in the management of stigma by family caregivers and the person with dementia. The first phase involves collusion with the person early on in the illness. Consistent with Goffman's (1963) earlier theory the person initially hides the signs of dementia from carers/family members who eventually recognise that the person has been 'passing', i.e. withholding information. The caregiver becomes involved in collusive passing to manage information to preserve the public face of the person with dementia and family (Blum, 1991). Three types of collusive passing are described – standing by, preventive passing and active passing. The caregiver also engages in three types of 'covering' (avoidance, preventative and remedial) to minimise the relevance of the stigma, its consequences and related embarrassment, as it becomes more visible. As the person with Alzheimer's disease becomes less able to co-operate a shift in the management of stigma occurs. In this second stage information is disclosed to others on an incident by incident basis, initially to seek assistance and validation, then to friends and when left with no choice to strangers in a pre-emptive and remedial way. The caregiver thus becomes the manager of both information and social control (Blum, 1991).

More recently Mac Rae (1999) in Nova Scotia, studied 47 family members of persons with Alzheimer's disease. Consistent with Blum's (1991) findings, covering up the discreditable condition was a stigma management strategy employed to address the risk of acquiring courtesy stigma. Other strategies included interpreting problematic behaviours as symptoms of the illness (beyond the control of the person with

Alzheimer's) and neutralisation where if 'others' became uncomfortable in the presence of the person, then family members felt it was the 'others' problem. The latter strategy was particularly evident among younger family members. It was suggested that this may be due to a change in younger cohorts societal perceptions of Alzheimer's disease, as an illness less likely to be stigmatising. Findings further suggested that some family members successfully avoid stigma, while others address stigma if it occurs. MacRae (1999: 60) also contended that family members can avoid stigma if they can "manipulate or control the definition of the situation so that others' reactions will not be negative". The mediating factor in this process was found to be the support of others who are in the know but are non-judgemental, sympathetic and in the words of Goffman (1963: 97) "serve as a protective circle".

## **2.7 Health professionals and stigma**

Healthcare professionals have been implicated in the construction and perpetuation of stigma (Whitehead et al., 2001; Craig et al., 2002; Chapple, Ziebland and McPherson, 2004). Wahl (1999) found that mental health caregivers repeatedly identified professionals, as contributing to stigma by making disparaging remarks and through behaviours. Angermeyer, Schulze and Dietrich (2003) report similar findings (see 2.6.1). In contrast, O'Connell (2005) writes that consultants of geriatric medicine and psychiatrists of later life in the main adopt a multi-dimensional holistic approach to care for people with dementia. The context of primary care for people with dementia is however suggested to present a particular challenge. The INTERDEM group (Myrra et al., 2005), in a European Union study, found that stigma associated with dementia was a pivotal factor in delaying diagnosis. Olafsdottir, Skoog and Marcusson (2000) found that a belief of no benefit to diagnosis and time constraints may have related to low GP detection rates, while Wolff, Woods and Reid (1995) reported that GPs felt they had little to offer, early specialist referral was not particularly helpful and dementia was mainly a social problem.

More recently Iliffe et al. (2005), in a study involving eight European countries, highlighted that GP exposure to dementia, difficulty in diagnosis, their own fear of the illness, embarrassment about the disclosure of memory and functional loss and a reluctance to negatively impact on long-standing relationships with patients affected diagnosis and response to dementia. In contrast Milne et al. (2000), reported consistency between a positive belief in the value of early diagnosis and reported practice. Three variables predicted practice – belief in patient benefit from early diagnosis, the possibility of negative outcomes from a failure to diagnose early and local support service accessibility. The researchers highlighted that a narrow definition of ‘treatment’ could limit care, as GPs who reported early diagnosis used a broader definition of treatment including; assessment, referral, care package planning and carer support. In countries with well developed dementia care services, Myrra et al. (2005) further found that dementia related stigma was less prominent. Such research is significant due to concerns relating to timely dementia diagnosis and referral and the pivotal role of GPs in this process.

Once made, reluctance to disclose a diagnosis of dementia is also a feature of the research. Variability in relation to attitudes, beliefs and practices relating to diagnostic disclosure were reported by Bamford et al. (2004) in their review. Stigma was identified as influencing disclosure in six of the studies. In Ireland, a nationwide survey of GPs found that only 6% stated they always disclosed a dementia diagnosis to patients and 13% often disclosed a diagnosis (Cahill et al., 2006). One of the reasons cited was concern relating to the impact of the diagnosis due to dementia related stigma. Some writers suggest that diagnostic labels can lead to stigma for service users and their families (Jones et al., 1994) and that they are constitutive of peoples’ lives (Gillman, Heyman and Swain, 2000). Others suggest that labels can be positive, as they may decrease blame and increase sympathy (Weiner, 1993, as cited by Wadley and Haley, 2001). In an Alabama study of 221 undergraduate female psychology students (using case study vignettes), participants associated a diagnosis of Alzheimer’s disease with greater sympathy, less anger, judgement of responsibility and greater willingness to help than with major depression (Wadley and Haley, 2001). Such research suggests that health

professionals should perhaps be less concerned about stigmatising people by assigning a diagnosis.

## **2.8 Addressing stigma**

Myrra et al. (2005) suggest that the processes by which de-stigmatisation can occur at personal, organisational and societal levels have yet to be properly understood. A multitude of interventions are advocated to address stigma.<sup>4</sup>

### *2.8.1 Education*

According to Byrne (2000) the starting point for stigma reduction is to close the knowledge gap via education. Accounts from those affected by stigma illustrate that health professionals may possess an insufficient knowledge base, which could contribute to the perpetuation of stigma. Professional knowledge could be augmented with reference to the knowledge and experience of relatives/carers. Public education campaigns delivered via a variety of methods are also advocated. These interventions need to be targeted at groups which are accessible and homogeneous (Warner, 2005). However while some researchers have found public education to be effective in the short term, others found that it lacked effect, effects were difficult to sustain and that provision of information may not necessarily lead to attitude change (e.g. Penn et al., 1999; Corrigan and Penn, 1999; Corrigan et al., 2001; Angermeyer and Dietrich, 2005). Consequently, long term, programmes of education which challenge beliefs and attitudes will need to be combined with other interventions to reduce discrimination.

### *2.8.2 Contact*

A growing body of research suggests that direct contact with persons who are stigmatised can reduce stigma (Corrigan et al., 2001; Morgan et al., 2002; Alexander and Link, 2003; Couture and Penn, 2003). Contact may increase understanding and challenge attitudes

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<sup>4</sup> See Estroff et al. (2004) for an analysis of programmes designed to reduce stigma associated with mental health issues. These writers have reviewed existing programmes using an expert panel and summate the exemplary qualities of such programmes.

Warner (2005) describes the use of social marketing campaigns by the World Psychiatric Association to reduce stigma and discrimination.

and beliefs. Through personal and professional encounters with persons who are subject to stigma, fear can be reduced and people may be less likely to want to be socially distanced (Alexander and Link, 2003). This approach offers the potential to combine information provision and direct interaction and is advocated as a promising strategy (Corrigan and Penn, 1999). With respect to dementia participants in Morgan et al's. (2002) Canadian study, suggested that contact would be one way in which to raise public awareness, educate and break down the fear and misunderstanding surrounding dementia. Innovative ways of facilitating contact between people with dementia and healthcare professionals are available, for example Knauss and Moyer (2006) refer to Northwestern University Hospital where a first year medical student becomes a buddy with a person with early stage Alzheimer's disease.

### *2.8.3 Media campaigns*

Discrimination can be linked to genuine misunderstanding particularly as a result of stereotypical representations, ingrained in all types of media, to the extent that the stereotypes can seem impossible to dispel (Penn and Wykes, 2003). A number of specific roles which the media might play in terms of action against stigma have been outlined. Examples include: policies to avoid disseminating stigmatising and discriminatory material, being aware of the potential to create myths, recognition of media responsibility to be informed, promotion of truth and reporting of appropriate information, raising the need for and awareness of services, supports and associations (Graham et al., 2003).

### *2.8.4 Legislative, advocacy and human rights approaches*

Legislation which imposes sanctions on those who exhibit "gross discriminatory behaviour" and legislation which promotes positive discrimination is advocated to address stigma (Haghighat, 2001: 212). However Haghighat (2001) suggests that there is scant evidence that anti-discrimination legislation will affect public stereotypes. Graham et al. (2003), referring to stigma and older persons with mental health disorders, acknowledge the primary responsibility of governments, however they also recognise the role of individuals and other groups (e.g. policymakers, Non-Government Organisations

at local, national and international level, professionals, carers and family members, persons subject to stigma, the general public, media, corporate sector and schools, universities etc). Legislative systems need to be challenged via lobbying and advocacy. It has been reported that poor quality services are one of the most stigmatising experiences and Angermeyer, Schulze and Dietrich (2003) suggest that advocacy groups have a specific contribution to the improvement of for example mental health services via external quality control and resource allocation functions.

By participating in political lobbying and decision-making, it is suggested that advocacy groups can engage in anti-stigma campaigns that may reduce structural discrimination (see 2.5.2) (Angermeyer, Schulze and Dietrich, 2003). Examples of anti-stigma campaigns include: the European Federation of Associations of Families of People with Mental Illness (UFAMI) ZeroStigma campaign and the National Institute for Mental Health in England 2004-2009 initiative SHIFT and in relation to dementia, the Dementia Advocacy and Support Network (DASN) International. While there is debate around the suitability of various models of advocacy (Cantley and Bowes, 2004), advocacy and collective action for people with dementia is posited as a way in which to enable participation in care planning and as a means to improve quality of life for self and others (Dementia Advocacy Support Network International, 2006, Sep 1). Knauss and Moyer (2006) describe their roles as dementia advocates in the United States and the many forms this has taken including; supporting and being supported by other people with dementia and sharing their personal wisdom with health workers, researchers and policy makers.

## **2.11 Summary**

While a universal definition of stigma was not located, stigma is clearly a multidimensional concept related to a perception of difference (self-perception and/or by others). This difference is accompanied by cognitive, affective and behavioural processes which can result in stigmatisation at an individual and societal level. Stigma and stigmatisation can take multiple forms (e.g. impediments to social participation, rejection,

devaluation, disempowerment and discrimination) and are potentially experienced in relation to diagnosis, treatment, disclosure and social contexts. The attribution of stigma may have consequences for health status, quality of life and health and social care policy. Stigma consequently requires exploration from multiple perspectives, in particular the reality for those affected including; people with dementia, family/carers of people with dementia, and health and social care providers. From an Irish perspective there is a paucity of research exploring the potential existence and experience of stigma in relation to dementia. There is a consequent need to understand and appreciate the nature of stigma in dementia, its effects and to potentially develop interventions to guide policy development, practice and future research.

## **Chapter 3 - Research Methodology and Participant Profile**

### **3.1 Introduction**

This chapter describes the study and the methods employed to carry out the research. The research approach is identified and the rationale for its use presented. Issues pertaining to sampling, data collection, data analysis and rigour are described. Due to the nature of the research and the vulnerability of the participants, some time is devoted to setting out the ethical considerations addressed during the research process. This study was commissioned by the Alzheimer Society of Ireland who wished to explore the issue of stigma related to dementia and the impact on those affected (person with dementia and carer/family members). The study was completed between March and September 2006 (appendix 2). The study aim and objectives reflect those outlined in the tender document and were later refined by the research team in conjunction with the Society.

### **3.2 Aim of the study**

- To conduct an exploratory study of stigma in dementia and the impact on all those affected, i.e. the person with dementia and his/her carer/family members.

### **3.3 Objectives**

- To utilise grounded theory methods to gain an understanding of the concept of stigma in the context of disability and dementia
- To examine the elements that lead to the construction of stigma in dementia and to understand their manifestation and application in day-to-day life
- To explore the specific concepts of fear and discrimination associated with dementia as a disability
- To identify potential strategies to deconstruct stigma associated with dementia

### **3.4 Research approach**

Consistent with the requirement of the research tender, to employ a sociological method of analysis to facilitate understanding of dementia related stigma, grounded theory methods were chosen to predominantly inform the conduct of the study. It is suggested that research relating to stigma has not sufficiently accounted for experiences of social relations and that terms such as stigmatisation are often used with no analysis of the social process involved (Prior et al., 2003; Grytten and Maseide, 2005). Research is required that is grounded in the lived experiences of those who are affected by dementia and who potentially experience and/or contribute to the existence of dementia related stigma. Grounded theory is widely used in health and social sciences research to distil issues of importance to people, to create meaning and build theory (Mills, Bonner and Francis, 2006). Grounded theory is designed to discover what is there to be known and what emerges from the research process. It offers a means to understand peoples concerns and how these concerns are actively managed (McCallin, 2003). Consequently, using this practical research approach, it was anticipated that knowledge relating to the experience of dementia and potentially the causes, conditions, contexts and consequences of dementia related stigma and the processes involved in stigmatisation would emerge.

### **3.5 Sample**

Due to the nature of the research and the parameters specified in the research tender, non-probability sampling methods consistent with grounded theory were utilised to identify participants with knowledge and experience of the social processes relating to dementia. In the initial stages, purposive sampling was used and as concepts and categories emerged, a theoretical sampling technique continued in order to attain data saturation (Streubert Speziale and Carpenter, 2003).

#### *3.5.1 People with dementia and/or family/carers*

In order to access potential participants with a dementia and/or carers/family members, gatekeepers from the Alzheimer Society of Ireland (not involved in the conduct of the study) approached potential participants, who fulfilled the study inclusion criteria and gave them the letter of invitation and pertinent study information sheets (appendix 3).

Gatekeepers acted as a liaison between the researcher and potential participants. Their role was to ensure that potential participants would not be exposed to inappropriate or excessive demands due to the research (Mander, 1992). If a person with dementia and/or carer/family member wished to discuss participation, they completed the bottom portion of the letter of invitation and returned it to the researcher in the addressed envelope provided. Potential participants were then contacted by the researcher to discuss participation.

### *3.5.2 Allied health professionals and disability organisation participants*

Allied health professionals and representatives of disability organisations or other agencies with knowledge and/or experience of stigma and/or dementia, who fulfilled the study inclusion criteria, were selected by members of the research team in consultation with a representative of the Alzheimer Society of Ireland (appendix 3). This method of selection was designed to ensure that participants with particular knowledge and expertise who could enhance understanding of the research subject, from a multiplicity of perspectives, were included. In order to access the identified persons, a letter of invitation and relevant study information sheet was forwarded to them for their consideration. If a potential participant wished to discuss participation, they then completed the bottom portion of the letter of invitation and returned it to the researcher in the addressed envelope provided. Potential participants were then contacted by the researcher to discuss participation. Where an individual was interviewed in their place of work, permission to access the workplace was firstly sought from the appropriate employer.

## **3.6 Participant profile**

In addition to the research interviews some background contextual information was collected in the course of the study (appendices 4 to 6). So as to ensure informational adequacy and in light of the time available to complete the study, a maximum sample size of 25 interviews was proposed at the study outset. In total 23 interviews were conducted with 24 participants, in both rural and urban contexts, across a number of geographic areas.

### 3.6.1 Person with dementia

One interview was conducted with a person with dementia. This participant lived in an urban area and had availed of or was currently accessing the following services; consultant (type not specified), memory clinic, the Alzheimer Society of Ireland and a carer for 3 hours per week. The participant chose to have a family member present who also consented to participate in the study.

### 3.6.2 Carer/family member participants

Twelve interviews were conducted with carer/family members. Ten of the participants were currently caring for persons with dementia and the relatives of two of the participants were deceased. The majority of the participants (n=10) lived in urban settings. The number of years that carers/family members had been providing care or had provided care for people with dementia ranged from 4 to 15 years. Table 3.1 provides an overview of the study participants by age and sex. Most of the carers/family members interviewed were female. Participants' were aged from 36 years to 86 years representing a spread of 50 years. This is a notable contextual factor when considering the study findings.

**Table 3.1 Carer/family member participants by age and sex**

	<b>Male numbers</b>	<b>Female numbers</b>
<b>30 - 39</b>	0	2
<b>40 - 49</b>	0	1
<b>50 - 59</b>	1	3
<b>60 - 69</b>	0	1
<b>70 - 79</b>	1	2
<b>80 - 89</b>	1	0
<b>Total</b>	3	9

There was variability with regard to the nature of the relationship of carers/family members to people with dementia.

**Table 3.2 Carer/family member relationship to the person with dementia**

<b>Relationship to the person with dementia</b>	<b>Number of participants</b>
Wife	4
Husband	2
Daughter	5
Son-in-law	1

Where known carers/family members were asked to provide detail in relation to the type of dementia their relation had been diagnosed with. As seen in table 3.3 the most frequently known dementia diagnosis was that of Alzheimer’s disease.

**Table 3.3 Type of dementia diagnosed**

<b>Dementia type</b>	<b>Persons with dementia</b>
Alzheimer’s disease	8
Vascular dementia	1
Fronto-temporal dementia	1
Unknown	2

Carer/family member participants were also asked for details of the services they were currently accessing or had accessed. All participants had contacted the Alzheimer Society of Ireland, either for information, support or service purposes.

**Table 3.4 Services accessed by carer/family member participants**

<b>Service type</b>	<b>Participant numbers</b>
Alzheimer Society of Ireland	12
Day care services	9
Medical Consultant (type not specified)	12
Carer coming in to the home	7
Respite services	7
Nursing home – public	1
Nursing home - private	2

**3.6.3 Allied health professional and disability organisation participants**

Nine interviews were conducted with allied health professional participants and one interview was conducted with a representative of a disability organisation. Nine of the 10 participants in this sub-group had direct experience of working in dementia care. The tenth participant (representing the disability field) did not have specific experience of dementia or dementia care but had experience of stigma related concepts. Table 3.5 shows the general occupational designation of the participants and where applicable the number of years of dementia specific care experience. Of note a few of these participants also spoke about their personal experiences of caring for a close family member with dementia.

**Table 3.5 Allied health professional and disability organisation participant occupation and dementia specific experience**

<b>Participant Occupation</b>	<b>Years of dementia specific professional care experience</b>
Social worker	14
Senior psychologist	1

<b>Participant Occupation</b>	<b>Years of dementia specific professional care experience</b>
Day care manager	7
Consultant geriatrician	20
General practitioner	30
Dementia home care co-ordinator	4.5
Dementia care co-ordinator	17
Carer support resource	20
Social worker dementia organisation	20
Disability organisation representative	Not applicable

### **3.7 Ethical Considerations**

The research team were very aware that participants in the study were drawn from vulnerable populations and that recounting experiences of dementia and potential experiences of stigma could have been an emotionally challenging experience. A multistage approach to address ethical concerns was consequently adopted.

#### *3.7.1 Phase 1*

- Ethical approval for the study was obtained from the Ethics Committee of the Faculty for Health Sciences, Trinity College Dublin.

#### *3.7.2 Phase 2*

- Gatekeepers (where appropriate) were utilised to facilitate access to the sample, so as to protect the interests of potential participants and ensure their voluntary participation.
- Potential participants were sent, a letter of invitation to participate in the study and an information leaflet.
- When designing the information leaflet, the readability, content, font size, length and spacing of the leaflet given to be given to people with dementia was considered.

### 3.7.3 Phase 3

- In order to protect the rights of people with dementia, the researcher met with each potential participant and carer/family member where appropriate.
- The nature and purpose of the research and what involvement in the study entailed was explained in a sensitive and unhurried manner.

### 3.7.4 Phase 4

- Consent to participate was obtained in writing from all participants prior to conducting the research interviews.
- A tick box consent form was designed to enhance the readability of the consent form and reduce the complexity of the decision-making process to a series of simple steps presented in a logical sequence.
- A process approach to consent was also utilised, involving ongoing assurance of participants' wish (and where necessary capacity) to participate.
- In order to uphold participant anonymity and confidentiality, each participant was assigned a code at the time of his/her enrolment in the study, by which they were referred to from that point on.
- Data were stored in keeping with the Data Protection Act (Government of Ireland, 2003).
- The participant with dementia was afforded the opportunity to participate in the interview in the presence of a carer/family member.
- If any indication of upset emerged during an interview, it was decided to discontinue the interview, and only resume if and when participants were ready.
- Participants were also provided with information on support services available through the Alzheimer Society of Ireland, as required.

## 3.8 Data collection

### 3.8.1 Data collection instruments - interview guides

Data was gathered using semi-structured non-directive interview guides (appendices 7 and 8), as highly structured data collection methods are inconsistent with grounded

theory and would have been less likely to enable participants to explain the meaning of their responses. The interview guides were developed to address the study aim and objectives and contained topic areas designed to facilitate exploration of dementia experience and potentially identify the existence and experience of dementia related stigma. Several probes were included to encourage participant elaboration.

### *3.8.2 Piloting of the interview protocol*

A pilot study consisting of three administrations of the interview protocol was conducted. The purpose of these pilot interviews was to test the suitability and feasibility of the interview guides and procedures prior to the main study and to refine the interview process by identifying and addressing any problematic areas (Mead, 1993). The experience gained from the pilot process demonstrated that the level of cognitive and affective engagement required for the research interviews was significant and led to more realistic expectations during later data collection. The pilot process also highlighted the need for minor adjustments to the topic guides and reduced researcher self-consciousness in the research interviews.

### *3.8.3 The interview process*

The interviews were conducted in a systematic yet flexible manner. Interviews ranged from 16 to 43 minutes and were held in a place and time of convenience for the individual participant, for example, a person's office or home. All of the interviews were digitally recorded with participants' permission and then professionally transcribed. The recorded interviews provided an accurate record of participants' experiences and were critical in the research teams approach to addressing issues of rigour in terms of the findings. The researcher also recorded field notes after each interview. The field notes referred to points of significance relating to the interview contexts, content and processes and were used as a further data source for analysis. Throughout the interviews, the researcher and principal investigator listened to each interview, as it was completed, and ongoing discussion within the research team ensured that the interview process was adjusted if required. The interview guides were therefore used in an organic manner.

In order to avoid influencing participant responses, overuse of the word stigma was avoided during data collection. Flexibility was employed by the interviewer and the direction of the interviews was led by the nature of participants' responses in addition to the interview guides. A conversational approach and the building of rapport and genuine interest on the part of the researcher, was used to create an open, honest and supportive environment. This facilitated the exploration of issues of concern without interviewer influence, constraint or direction. Probing and clarification was determined by interviewer sensitivity to participants and the emergent data (Charmaz, 1994, cited in Wimpenny and Gass, 2000). Later interviews were also informed and sharpened by emergent categories and existing theory.

### **3.9 Data analysis**

The procedures utilised to inform data analysis were consistent with the grounded theory methods described by Glaser and Strauss (1967) and Glaser's later editions (1992; 1998). The overall approach involved simultaneous data collection and constant comparative analysis, coding, identification of categories and their properties and theory generation (Jeon, 2004). Throughout the study, memoing (theorising write up of ideas) and the keeping of a reflective diary by the researcher were critical in the facilitation of researcher reflexivity and the development, elaboration and integration of categories. Initially transcripts were read repeatedly while listening to the interview recordings. This facilitated early researcher immersion in the data. Data was then subjected to manual line by line open coding to identify processes and assign initial substantive coded labels. The transcribed interviews were then imported into the NVivo 7 (QSR International, 2006) computer package and subjected to two further phases of analysis (appendix 9). The use of this programme assisted in the storage and management of data and also contributed to the creation of an audit trail illustrating the research process and emergent findings. Action codes (Charmaz, 2003) were initially employed to visualise interrelated processes in contrast to static isolated topics. As coding proceeded, these labels were organised to form categories, having identified and clustered similarities and differences. Categories

were then further organised into nine overarching themes and related categories (see Chapter Four).

### 3.10 Rigour

In order to address issues relating to rigour and ensure the trustworthiness of the data, the following were employed throughout the research process. The criteria originally devised by Glaser and Strauss (1967) and outlined in Table 3.5 were used as guides. The research findings and recommendations were primarily evaluated by considering the entirety of the research process and the way in which the essential components of the grounded theory approach impacted on the quality of the research (Elliott & Lazenbatt, 2005). To augment this process, peer debriefing, involving members of the research team (not involved in the collection or analysis of the data), acting as critical friends was employed. This was designed “to stimulate consideration and exploration of additional perspectives and explanations at various stages...of data collection and analysis” (Long and Johnson, 2000: 34). The process of peer debriefing also contributed to the theoretical sensitivity central to the conduct of grounded theory. The ultimate aim was to ensure that the category analysis was accurate and that the emergent findings fit the data.

**Table 3.6 Criteria used to guide the evaluation of the study findings (adapted from Glaser and Strauss, 1967)**

- **Fit** – the theory produced should fit the data from which it emerges and not be derived from pre-existing theoretical perspectives
- **Work** – the theory needs to provide a pragmatic organisation of data which explains the substantive area to which it pertains
- **Relevance** – the theory should be general enough to be applied in varied daily contexts
- **Modifiability** – the theory is modifiable in light of conditional changes or the acquisition of further data

### **3.12 Summary**

This chapter outlined the research approach and methods employed during the conduct of the study. Specifically the grounded theory approach described by Glaser and Strauss (1967) and Glaser (1992; 1998) and methods consistent with this approach were utilised to inform the research process. In the next chapter, the research findings are presented.

# Chapter Four – Presentation of Findings

## 4.1 Introduction

This chapter presents the findings of the research. The findings represent an initial subjective exploration of stigma and dementia from the perspective of the individuals interviewed. It is important to reiterate the exploratory nature of this study. Findings should consequently be interpreted with caution. Following data analysis, nine themes emerged. Table 4.1 presents an overview of the thematic structure and the sub-categories under which the findings will be presented. For this presentation of the findings, the views of the three participant sub-groups are integrated and presented under the thematic structure. This was considered important in order to provide a comprehensive picture of the emergent issues. Anonymised direct quotations, where appropriate, are used to provide context and illustrate the issues discussed.

**Table 4.1 Research themes and sub-categories**

<p><b>1. Stigma and discrimination – is there or isn't there?</b></p> <p><b>2. A dark secret still</b></p> <ul style="list-style-type: none"><li>• Images and associations</li><li>• Labelling and the power of words</li><li>• Fear and avoidance</li></ul> <p><b>3. Behind the closed door – the reality of dementia</b></p> <ul style="list-style-type: none"><li>• From denial to acceptance</li><li>• Emotional reactions</li><li>• Experience and knowing</li><li>• The impact on the family</li></ul>
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#### **4. Loss of place**

- A lesser being – becoming invisible
- A different life – social isolation
- Loss of carers' previous ways of being
- Caring for self and being cared for

#### **5. Navigating the system**

- The journey
- Finding my way

#### **6. Making safe – constant vigilance**

- To tell or not to tell
- Protecting the person with dementia
- Protecting close others

#### **7. “Double whammy” – ageism and dementia**

#### **8. Viewing dementia as a disability**

#### **9. The future – dementia ready**

### **4.2 Stigma and discrimination – is there or isn't there?**

Stigma was clearly an issue for a number of the participants and was perceived by some to be similar to the stigma associated with mental health illnesses:

*“... I think that it is still a very stigmatising illness ... in Ireland I think in particular it's more stigmatising ...”* [AHPDO7]

*“once you are diagnosed with mental health [illness] there's this huge stigma”*  
[CFM05]

The issue of the damage that stems from living with a stigmatised illness or condition is strong in the literature, but this is experienced in multiple and complex ways. Participants in this study suggested that dementia related stigma could be damaging to those directly affected, including CFMs and potentially impact on personhood. At the same time, stigma did not appear to be an all encompassing issue for other participants. Such persons either did not associate stigma with dementia or demonstrated a greater identification with its components, such as labelling, negative imagery, stereotyping, avoidance, social isolation and service difficulties, rather than the overall concept. This was true for all three groups interviewed. Interestingly, the data suggested that for some CFMs, as dementia progresses, their early stigma related concerns may be replaced with a focus on more pragmatic day to day issues:

*“... I think it’s at the early stages, I think it is, because then you get to know more ... and I think you learn to accept things...”* [CFM09]

*“She was walking from the back door to the front door and she was pulling the handle off the door... She wouldn’t sit down. She’d sleep maybe an hour a night”* [CFM12]

One allied health professional suggested that using the term stigma could be problematic and reinforce or contribute to a perception of dementia as being a stigmatising illness:

*“If it’s spoken about often enough it will be an issue, if people say there is stigma attached to dementia then there will be stigma attached to it”* [AHPDO5]

Similarly, another allied health participant [AHPDO10] suggested that focusing on stigma could be an impediment to addressing related issues, such as discrimination and prejudice. This participant proposed that perhaps professionals should alternatively focus on discrimination and prejudice, which could reframe stigma and dementia as social issues that demand a society-wide response. This could potentially create the possibility to progress social change. Participants had varied perspectives as to whether there is or is not dementia linked discrimination. While the existence of discrimination was described

by some, particularly in relation to service provision, i.e. structural discrimination, it was generally felt that this was not a deliberate act but rather due to dementia not being a priority in terms of policy and sufficient resource allocation:

*“I’m not sure about discrimination. It’s a terribly, terribly difficult thing because you could be discriminated against for all sorts of causes. I don’t know that the Alzheimer’s discrimination is worse than anything else...”* [PWD1]

*“...at a deeper and wider level important in terms of the failure to face up to and develop services”* [AHPDO8]

### **4.3 “A dark secret still”**

This theme consists of three sub-categories and relates to the finding that despite advancements in knowledge and ways in which to address the illness, dementia continues to be associated with some social unacceptability and as a result can remain hidden.

#### *4.3.1 Images and associations*

The three groups frequently referred to images, stereotypes and associations that people have relating to dementia. A number of negative stereotypes were described as potentially contributing to the stigmatisation of people with dementia. These included public perceptions of the intelligibility of people with dementia and their ability to participate socially:

*“Well this person now has a mental disability and they won’t be able to communicate with us”* [AHPDO6]

A number of AHPDO participants also referred to their experiences of a worrying and commonly held image that persons with dementia are violent:

*“I think if somebody has encountered a person with dementia who may have exhibited embarrassing behaviour or dangerous behaviour or disinhibitive behaviour then that ... is often the kind of most coded memory they have ... then they associate all people with dementia as behaving like this”* [AHPDO7]

Perceptions of people with dementia were linked by some to childhood and upbringing, suggesting the powerful impact that culture may have on the acquisition of beliefs and attitudes in relation to dementia:

*“I mean with what I grew up with, I mean, I was reasonably I suppose educated individual and I mean dementia always meant to me insanity”* [CFM03]

*“it comes historically because people with dementia were seen as in their doting, “for the birds””* [AHPDO5]

Media images of dementia were also described. Two contrasting perspectives emerged. A number of participants referred to the positive role that the media can and have played in portraying dementia and facilitating understanding. Recent advertisement campaigns, use of the internet as an information resource and the recent dementia storyline in Coronation Street were cited as examples of potentially positive advancements. One participant suggested how important it was that media accounts of dementia should illustrate the reality of the dementia experience:

*“the ads now they do are good, Coronation Street did a good job, but I think they should have went more, I know they probably hadn’t got the space”* [CFM10]

In contrast one participant spoke about the potential for the media to contribute to negative stereotypes of dementia. This participant suggested that if negative messages are displayed, these can be incorporated into the identity of the person with dementia:

*“the media and its role and especially around something where you start to get a link between a condition and violent behaviour. The media can really latch onto that and can expand its providence so to speak, cos of the numbers of people that have access to media and ... anything that is related to violence is attractive to the media”* [AHPDO10]

Although early onset dementia (i.e. people with dementia who are under 65 years of age) was not the specific focus of this study, a number of participants referred to stigma related issues in relation to this age group. Some participants suggested that images of

dementia, as an illness associated with later life negatively impact on the awareness of and the particular experiences and needs of younger people with dementia:

*“it’s the awareness, we always think of somebody with dementia it’s like somebody’s granny or somebody’s grandfather, we don’t necessarily think of it as somebody’s son or daughter or a younger man or woman ... I think it’s the marketing of it, it tends to be more for older people”* [AHPDO3]

#### 4.3.2. Labelling and the power of words

Use of terminology and its impact emerged as a particular consideration for many of the CFM and AHPDO participants. Some of the terminology used in relation to dementia seemed to be linked to images and stereotypes of dementia. A number of terms used to refer to dementia were mentioned, for example, ‘the wanderer, walkers’ [CFM01], ‘senility’ [CFM01], ‘doting’ [CFM03], ‘a living death’ [CFM03], ‘an everlasting funeral’ [AHPDO1] and ‘never ending funeral’ [AHPDO7]. In relation to the more correct terms to use, one participant [CFM05] spoke about her confusion when trying to locate support and information, as she initially thought that the Alzheimer society only provided assistance for those diagnosed with Alzheimer disease and not dementia. However for others the word Alzheimer’s was noted to be more appropriate, as the word dementia was suggested to connote madness. There therefore appears to be some debate about the correct or more desirable term(s) to use:

*“... when it’s called dementia, you know, is it that dementia became such a stigmatised word, we better get a nicer one like Alzheimer’s”* [CFM11]

*“... there’s been lots of debates about terminology, whether dementia, the term dementia, is kind of a more kind of socially accepted you know disease label than Alzheimer’s disease or vice versa and I’ve heard people kind of arguing both sides”* [AHPDO7]

The issue of labelling was also raised. Some participants referred to the effects of assigning a label of dementia to a person. While it was recognised that this can be a

necessity to access services, the potentially negative sides of label assignation were also indicated:

*“... I think in mental health they are more and more moving away from those kinds of things ... doctors are shying away from assigning diagnosis because of the prejudice”* [AHPDO10]

*“there’s so many connotations, there’s so much at stake. I suppose that it’s really the younger person and their family and how they accept it, and financial implications and everything else attached to it”* [AHPDO5]

### 4.3.3 Fear and avoidance

Fear of dementia was an issue which many participants spoke about. A perception of difference was described. In the words of one participant who described societal beliefs about people with dementia:

*“... they are not quite like us”* [AHPDO2]

Dementia related fear was explained in a number of ways: being faced with one’s own mortality, a fear of catching or developing dementia and lack of understanding were described:

*“I think I’ve got what daddy’s got”, the worry is there, you know”* [CFM09]

*“To a degree, and I think it’s more through fear of seeing that the possibility that this could happen to me””* [AHPDO4]

*“... it’s the lack of education and the lack of knowledge as to what it means you know”* [AHPDO6]

Linked to fear was a consequent tendency to avoid people with dementia:

*“I think it might make people withdraw”* [CFM03]

*“They stand back because it’s too heavy type of thing you know, that’s the way I would look at it”* [CFM11]

It was suggested that people might be reluctant to engage with people with dementia, as they may fear they will be expected to become involved or because they do not know what to do or how to cope:

*“ ... people just don't know how to behave how to react, how to talk to someone with dementia”* [AHPDO7]

One participant spoke about fear and avoidance reactions in health professionals and how experience had demonstrated their reluctance to openly engage with the related issues in practice:

*“I can see also that within the caring professions people are uneasy about speaking about dementia openly in front of people ... so I think we're at the stage where people, it's sort of a dark secret still”* [AHPDO8]

#### **4.4 Behind the closed door – the reality of dementia**

Participants, in particular the PWD, this person's carer/family member and the CFM group, did not always separate the overall experience of dementia from the complexity of stigma and dementia. Stigma (or its components) appeared to be embedded in the overall experience of dementia. The term stigma was used more frequently by the AHPDO participants to explain what was occurring. A number of the participants in this group spoke from a variety of perspectives, as they had personal experience of caring for a person with dementia. The findings which make up this theme illustrate the reality of the dementia experience where connections with stigma related considerations were identified.

##### *4.4.1 From denial to acceptance*

In order to cope, there is a need for acceptance of what is happening and of the changes that dementia brings. However denial is a reaction which seems to frequently accompany dementia. Most of the participants in this study described an initial denial reaction on the part of people with dementia and/or CFMs when they suspected the presence of dementia or once a diagnosis was confirmed:

*“I suppose they see what’s happening but they put the blinkers on and they say; “well I’m not going to, that’s over there that word and I’m not even want to look at that””* [AHPDO4]

Denial appeared to stem from two sources, firstly as a reaction to the diagnosis of an illness and secondly because of the particular associations and reactions from others that come with a diagnosis of dementia:

*“I knew right, but if I admitted it to myself, I would have to admit it to everyone else, right, and once I admitted it to myself, and the family, I would then have to admit it to the people outside the house.”* [CFM07]

*“Yeah even when people come in here first, it’s like the word Alzheimer’s sometimes it can be very taboo, “I don’t think they actually have Alzheimer’s” ... So they’re still in that denial phase ... “what would the neighbours think ...””* [AHPDO4]

Denial was reported to be a barrier to seeking diagnosis (see 4.6.1) and accessing services:

*“I suppose one of the things that we are quite conscious of here is that in terms of, as people get on in the process and families are trying to cope with them at home because they’re, I suppose not really accepting what is inevitable, then can actually hamper services, and even in the earlier stages if families don’t come onboard with the diagnosis then we can I suppose not really engage, not take advantage of respites and so on and burn out will happen more quickly”* [AHPDO3]

Acceptance therefore seems to be critical, comes with time and appears to require comfort with the diagnosis [AHPDO4], a letting go of the way things were and adjustment to a new and constantly changing way of life. The length of time this process takes appeared to be individual and cannot be forced, but the process can be enabled with the input of knowledgeable health professionals:

*“on top of any other stigma, so that can be a sort of a bit of a barrier so we have to do sometimes a lot of work in order for people to accept the diagnosis and sometimes it’s a matter of time, the actual family have to see that things are deteriorating before they’ll actually take any word for it ....”* [AHPDO3]

#### 4.4.2 Emotional reactions

Those affected by dementia experience a broad spectrum of emotions. Almost all of the participants referred in some way to the emotional sequelae experienced with dementia. Similar to the previous category, emotions related to two overarching issues. Firstly, as a consequence of the illness process and its progression; examples from the study included: initial shock followed by hope that this is not happening or that the diagnosis is not correct, anger, hopelessness and feeling that little can be done, tiredness and stress accompanying instrumental caring, incredulity that this could happen to someone this close and loneliness with the loss of the person:

*“... Because how could this, so well, fit young man, who had worked at a very responsible job all his life, and being very intelligent, possibly have a thing like that, it couldn’t be.”* [CFM07]

Secondly the emotions experienced can be linked to dementia related stigma or its components (see section 2.2). Generally, the emotions that were described in this study were not spoken of in a positive sense and the potential impact was succinctly highlighted by one participant:

*“the impact, the emotional impact that stigma can have for the person who is you know, who experiences a stigma and prejudice and I think that’s a fairly under-researched area and an area that’s not spoken about enough, but it’s kind of logical that if you experience stigma, that that’s going to affect you emotionally in a negative way.”* [AHPDO10]

Anger and hurt occurred with loss of social contacts (see sections 4.5.2 and 4.7.2), particularly those with whom close relationships would previously have existed. These losses could exacerbate loneliness experienced in relation to the changes that may occur in the relationship between the PWD and a CFM due to the illness. Anger and hurt may also be an issue when inadequate and unsuitable services or contacts with service personnel are experienced:

*“I might have had four or five but other friends, they couldn’t cope. And it was rather hurtful that they never phoned”* [AHPDO2]

*“I tried to be extremely nice, and after about the third or fourth [instance] of this, I just suddenly went, we went in this particular day, he said; “how are you today”, and I just couldn’t help myself, I said; “well we here because we’re extremely well, what do you want him to say”, right ...”* [CFM07]

A number of participants spoke about embarrassment and one person referred to shame [AHPDO10]. These emotions related to other people becoming aware of a dementia and incidents that could happen when out in public, which then expose a PWD or CFM to the consequent reactions of others:

*“I suppose but sometimes if I’m in a restaurant or if I’m in a shop she will do or say strange things or she’ll start talking to people she doesn’t know at all at a supermarket. And yet that does, I suppose it’s more kind of an embarrassment sometimes, oh god what is she gonna say now or I’m kinda on high alert sometimes because people do look kind of odd or strange...”* [CFM05]

Guilt was explicitly singled out by a number of the study participants as a significant issue. One participant reported having felt ashamed on initially hearing the diagnosis of a family member [CFM 10], while another participant reported feeling guilty when taking time out for herself [AHPDO5]. However, many CFM and AHPDO participants described another worrying form of dementia related guilt originating from a personal or societal expectation that one should be able to care for the person with dementia indefinitely at

home. If and/or when it becomes no longer possible to care for a person with dementia at home, guilt can ensue due to inability to meet this perceived expectation.

*“I also feel that, people talk about guilt, as regards, I mean to finally go to full time care, that the carers would feel guilt about that, I don’t think that’s right, and I don’t think that guilt should ever be mentioned to carers. If they’ve done their best, they’ve done their best ... So you don’t need somebody saying to you, “did you feel very bad about him going”, “did you feel very guilty about him going into care”, you don’t need that, and guilt is something I’ve always rejected.” [CFM02]*

#### 4.4.3 Experience and knowing

To truly appreciate the nature of dementia and its impact on the person, personal experience was noted as important in this study:

*“Most people don’t understand what Alzheimer’s is, it’s too complicated of a word, but you got to understand and then, well you’re trying to explain dementia. Then you try explain the difference between dementia and Alzheimer’s and people are lost and the only thing, the only people that understand is people that’s actually involved, and see it themselves.” [CFM01]*

To those without experience, it was proposed dementia can be simply a word and persons without personal experience may be subject to the issues illustrated in 4.3, including stereotypical images of people with dementia and fear and avoidance reactions, which contribute to and/or result from dementia related stigma. The findings suggest that if a person has experiential knowledge of dementia, then in a sense they potentially enter an inner circle of knowing. Those directly affected by dementia gain this experience and consequently understand the reality. They know about the positive and the negative aspects, what it means to care on a day by day basis and the unique impact and unpredictable nature of the illness on their loved one:

*“I don’t think that people really understand the extent, a lot of people just say to you like “she’s just getting a bit forgetful” ... even my mother-in-law like would say to me, “(NAME) I think you think too much about it” ... I know you see, I see the subtleties, you know, I see like the difference in just like even her vocabulary, I see the differences in the way that she deals with things, that like, if something important happens, that it just doesn’t have the same impact as it normally has, you know and all of those things.” [CFM04]*

Some participants also suggested that in society those who lack personal experience of dementia may possess a minimal or rudimentary understanding of what dementia is. Direct experience clearly makes the difference, between ‘knowing that’ and ‘knowing how’ and may potentially ameliorate the problematic dementia related images, stereotypes, labelling and other stigma related issues. However, this could also exacerbate the void between those that understand and those who do not and in turn might increase rather than decrease social distance between those affected by dementia and those not affected:

*“they don’t really know the ins and outs of it, but sure they don’t have to have any need to know because it’s not in their life, I mean the only reason like I know is because it’s been in my life for so long, and I mean maybe if it hadn’t, would I want to know about it either?” [CFM04]*

The importance of experience also related to health professionals. Knowledge and experience of specialist dementia care may enhance professional understanding and the provision of care, which meets the individualised needs of the PWD and CFMs. This was referred to by a number of the AHPDO participants in the study:

*“Obviously what I’ve learned, I’ve learned from other professionals and I suppose the greatest debt to people with dementia and families who have struggled and lived on a daily basis with this condition...I think textbooks are wonderful but you need to have the human story to hang the bits and pieces on the theories you read about” [AHPDO1]*

#### 4.4.4 *The impact on the family*

CFM and AHPDO participants spoke frequently about the impact of dementia on the family unit, in terms of both immediate and more extended family members. While there were many examples of positive family reactions and a unifying effect relating to dementia, the experience of some participants was that dementia had divided or fractured families:

*“It is very far-reaching for families but I think a lot for the families and that they split and they just leave it, like mine think it’s easier to leave it to me”* [CFM12]

*“the one thing that I do find with the Alzheimer’s disease, it can either make or break a family, it can unite a family where it’s a common goal and they will all support each other in the caring role and give assistance or what it can do is split a family...”* [AHPDO4]

While this might occur for many reasons, such as existing family relationships [AHPDO1 and AHPDO4], some participants in this study related negative family reactions in part to an inability to accept the presence of dementia and/or its implications:

*“ ... and family. I think the biggest, one of the biggest problems ... she has sisters ... some of them to this day won’t accept it. I mean they can see she clearly has it.”* [CFM05]

*“...but I think there is a thing about the family members being also affected by stigma and some of, I think there is definitely from conversation that I’ve had with people, there’s definitely issues around a family member resisting the person, the individual actually being public, being participating in public because of the family member’s fear around stigma so...”* [AHPDO10]

Two AHPDO participants in particular [AHPDO1 and AHPDO5], specifically outlined their roles in relation to meeting with and assisting families. It was suggested by one CFM participant that where families are spoken to, that this occur as a family unit so that everyone could receive the same information at the same time. This was posited as

helpful, especially where one family member assumes the primary caring role, so that they would not be associated with being the bearer of the news, as information would come through a different channel.

*“And I do think families should be, they should be all buy into, they should be made go to a meeting, and (inaudible – back ground noise), not be blaming me for what I tried to do for a peaceful life or a little bit better life for myself and my mother, you know.” [CFM10]*

## **4.5 Loss of place**

### *4.5.1 A lesser being – becoming invisible*

Participants from all three sub-groups commented on how persons with dementia are at risk of being perceived and treated as less valuable or invisible in society:

*“that person was now known, they were now quite a different person to the person they were ... They were now a lesser person and treated with lesser respect or their intellectual abilities were not seen, a disability was seen, was visualised” [AHPDO9]*

*“I think (laughing) ‘cos there’s no proper indication of what Alzheimer’s is, they never really know what to look for so what’s the point in looking at you!” [PWD1]*

The progression of the illness was spoken about by some CFMs in terms of loss due to the impact on the relationship between the person with dementia and the carer. This perceived loss could be compounded by instances of dehumanisation imposed by people in society with whom the person with dementia and their carer/family member come in contact. This was suggested to have significant implications on a person with dementia’s self-perception:

*“They talk to me but the way they talk to him, brings the attention and it becomes, all of a sudden, I feel we’ve become like a circus” [CFM07]*

*“ ... also the way people treat you really can damage your self confidence so the link between stigma and self confidence I think is really important” [AHPDO10]*

A number of participants were understandably very emotional when they were recounting how easy it is for others to speak about people with dementia rather than speak directly to them, as if they were not actually present. This occurred even in the company of long time associates and/or friends:

*“how are you, isn’t he great, look at him”, these kinds of silly...”* [CFM07]

*“He was standing there and she said, “ah he won’t know me after another time”, that’s all she could relate with Alzheimer’s ... they were talking through me, they weren’t talking to him”* [CFM09]

Of note, participants also described similar practices in relation to contact with service providers. While instances of excellence with professionals were highlighted, exemplars describing discrimination or dehumanising contacts were also recounted:

*“I find some of them are not respectful to them. Some of them just talk down to them ... I find it, an awful lot of people, maybe it’s more sort [of] with people in authority, they think they have the right to talk down to them ...”* [CFM12]

*“... the day before you have the diagnosis you’re Miss or Mr and you get the diagnosis and suddenly you are Dearie, what is that ...It is dehumanising and to have that dehumanising language and behaviour used by professionals is appalling”* [AHPDO9]

#### 4.5.2 A different life – social isolation

This category describes the withdrawal of friends, associates etc. and the barriers to social participation that the person with dementia and their carer/family member can face. Both of these issues, which in part may be related to dementia related stigma, can result in social isolation, a concept that resonated in the majority of participant responses. Life as it was before dementia diagnosis is different from that after diagnosis and continually changes as the illness progresses. In consequence, a shrinkage of social space (i.e.

accessible social contexts) and a progressively shrinking social network for those closest to the dementia experience was indicated:

*“ ... I mean it’s a different life completely”* [CFM03]

Withdrawal of social supports for the PWD and the CFM can occur internally where difficulties arise within a family sometimes due to difficulties in acceptance (see 4.4.4), but also when friends, neighbours, colleagues etc. withdraw. In relation to reducing contact with social networks, two possibilities emerged. The first was that people tend to melt away. At first they visit, then maybe telephone but gradually they stop coming. This in turn contributed to a form of enforced social isolation:

*“ ... there’s a lady across the road that my mother would have gone to, I mean they all see that she has it, they don’t come over to her, nobody calls to her anymore ... It is important because she does notice it in little ways, you know, she does mention it ...”* [CFM04]

In contrast some CFM participants reported that a core of friends remained, but those that stay may not necessarily be those one would have expected. The inevitability of diminished social contact and social participation seemed to be accepted by some participants:

*“I mean I wouldn’t resent it, I can quite understand it”* [CFM03]

It was evident that barriers to participation can be experienced by the PWD. This can be due to illness related factors where early on the person with dementia chooses to withdraw, but also where services, facilities and social environments do not support the person’s retained abilities:

*“...social participation can be inhibited again by society not enabling their level of cognitive abilities so if things are in an easy to read format, signs aren’t clear if markings in signage you know for directions isn’t clear then they are inhibited from being able to participate socially and I would imagine that that could affect people with dementia as well”* [AHPDO10]

Impediments to social participation can exacerbate social isolation, as individuals are excluded from community life. It appears that different types of person-centred services (that consider individual needs, desires, life history and biography) are required across the continuum of dementia in order to facilitate social participation:

*“if you’re approaching the response to their impairment by segregating them into a separate area of care you know a separate location, a separate site then you’re gonna be inhibiting their ability to participate in the community because the social activities are generally ... brought to them in the institution they’re not encouraged to go out into local community ...”* [AHPDO10]

*“I think it’s about misunderstanding of the condition, a feeling that if you have day-care centres established, what’s good for one is good for all...many of the public care settings do not have specialised dementia units attached to them ...”* [AHPDO1]

Social isolation may also have implications for a carer’s perception of place and self. One CFM no longer identified with her previous life. She had become cut off from the community and defined herself in terms of the caring role she now fulfilled:

*“... well, I just stopped doing them, I don’t do anything except care for him, I do nothing at all, I don’t go, I haven’t been out after ... eight at clock at night, in the past five years .. I am not anybody anymore except a carer”* [CFM07]

#### *4.5.3 Loss of carers previous way of being*

There is a profound impact of dementia and dementia related stigma on CFM’s lives. This finding concurs with the literature which addresses courtesy stigma or stigma by association (see section 2.6). Carers were not only coping with the consequences of a dementia illness on the person with dementia, but also the impact on the carer’s own quality of life and way of being. Stemming from the association with the person with dementia, CFMs are also subject to similar reactions from others. So just as the person with dementia experiences a redefinition of life-space, carers undergo that process of

redefinition as well. Many carers experienced significant role change, for example, a shift in relationship with the loved one or taking on the responsibility for activities they did not previously engage in:

*“he had the cheque book, he did any correspondence that had to be done, he did all that because he thought it was his role, he took up that role, write the Christmas cards, writing all the normal things, and then when he started to get forgetful, my mother had to take over that role”* [CFM01]

Some spousal CFMs spoke about experiencing the loss of their life partner due to the progressive nature of the illness. Children become carers for a parent where once this relationship was reversed. Interests engaged in before the onset of dementia may have to be discontinued, as the person no longer has the time or opportunity to engage in them. The CFM may also face difficulties where they try to continue their previous roles, as those without experience of dementia may not understand what they are going through or may not wish to engage in awareness of dementia related experiences. Carers may be forced to make a career change or indeed cease working in order to fulfil a caring role:

*“I was working, I was working nights and I was working, like I was in at two o’clock during the day so, and working right through maybe sometimes until two in the morning, ... I was just becoming more and more stressed, and worn down, and worried ... there’s just no way, I couldn’t continue doing that and look after mum, you know what I mean, because her needs became you know, too great”* [CFM04]

#### 4.5.4 Caring for self and being cared for

The impact of dementia on carers was clearly an important consideration. Direct and indirect references to caring for self and/or the need to care for self were made by almost all of the CFMs:

*“I rang her sister in the country who came up from the country and stayed with her for three days and I just went off on a break...”* [CFM05]

*“You have to keep going. You have to look yourself ...”* [CFM08]

The AHPDO group also highlighted the importance of enabling carers to care for themselves. To a large degree the requirement for carer support and self-care arose from the consequences of the nature and duration of caring for the person with dementia. This finding is consistent with the wealth of literature which addresses the impact of informal caring in dementia and the consequent need for carer support. However, for participants for whom dementia related stigma was an issue, there was an emergent sense that carers also need support to buffer the effects of such issues:

*“She wasn’t because she was screaming for help, but because people, neighbours didn’t ask because they were afraid she’d ask them for help, she now decided well I won’t ask for help so I’ll do all this and I’m in my box.” [AHPDO6]*

## **4.6 Navigating the system**

Many participants from all three groups referred to people with dementia and CFMs and their complex interactions and experiences with the health and social care system.

### *4.6.1 The journey*

The journey through the system almost always begins with the GP and the role of the GP was perceived as vital to the overall experience of dementia. Many CFMs reported very positive experiences and cited the GP as a primary support throughout the illness. Consistent with the literature (see section 2.7) however, delays in diagnosis and reluctance to impart a diagnosis, in part related to dementia related stigma, were also referred to, particularly by some in the AHPDO group:

*“I could not get the GP, and the GP he didn’t want because they were very friendly, he did not want to make that diagnosis ... Absolutely but you see on the ground when the primary was the GP, when they won’t accept it, that’s where you have the difficulty, you know that’s as basic as it is.” [AHPDO6]*

*“GP’s ...almost you know for professionals a stigma associated with diagnosing people and hence a reluctance to proceed with diagnosis.” [AHPDO7]*

The routes to diagnosis following the GP were also described, for example, memory clinic, psychiatry of later life and mental health services, geriatrician or neurologist. One participant suggested a designated dementia specific service, where all could be referred, a ‘Dementiaologist’ [AHPDO1]. Some spoke of a need to separate dementia services from the mental health services, due to the linked associations and stereotypes. And another participant described the value of services remaining as they are, as this provides choice so that the needs of the individual can be addressed. Some AHPDO participants also questioned the value of assigning a label of dementia because of the potential ramifications:

*“then if you then become categorised or labelled as being part of that then you know the mental health experience is that the person tends to absorb and that inhibits their own participation so in that sense there would be grounds for wondering whether assigning a diagnosis of dementia is a good thing or not.”*  
[AHPDO10]

Most participants spoke about the nature of the available services and how they were experienced. There was a general sense of improvement in service availability and praise for examples of excellence:

*“Yeah, I think it’s improved a lot, there’s more services available...”* [CFM02]

Insufficiencies and variability were however highlighted, particularly in relation to the availability of dementia specific services, for example, the number of specialist day centres and services to meet the specific needs of younger people with dementia. While generic services were indicated as potentially suitable for people in the early stages of dementia, as the illness progresses these services may no longer meet the needs and abilities of the person. This is an important consideration, as insufficient or unsuitable services could potentially augment and not reduce stress and mitigate against social participation and carer support:

*“We had to fight then to get him respite... and they told us we had to get him out of the unit, the respite unit ... look for a private nursing home, and that was a lot of stress, added to the stress, we were under at that time ...”* [CFM01]

*“I did tell the nurses there that he had Alzheimer’s and they asked me to stay with him, they couldn’t provide cover to mind him ...”* [CFM02]

Fragmentation, lack of flexibility and choice of services were highlighted as problematic by participants in all three groups:

*“I think it’s just not coming together”* [CFM05]

*“Resources are a huge issue, yeah, now I can’t give night or weekend service because I simply don’t have the funding,”* [AHPDO6]

The PWD and a number of participants in the CFM group also referred to a perceived gap in service provision, particularly after diagnosis and before advanced dementia, during which time participants were not sure where to go, what to expect or sometimes what is available:

*“‘Cos there’s this stage between being diagnosed and getting the full support from systems.”* [COPWD1]

*“I think there’s a big gap for someone like [name] who’s not so bad, to use that term, that she needs to be put in a nursing home or something and yet she’s not figured out what’s happening she seems to be in a kinda in-between...”* [CFM05]

Unhelpful experiences with professionals within the services were also mentioned. Some participants referred to the fact that sometimes professionals who should know may not know (for example not be able to supply information, may lack knowledge or dementia specific caring skills or demonstrate deficits in communication skills when interacting with people with dementia) or may demonstrate a lack of respect for the person:

*“...don’t seem to understand or this, just too many people and not one person dealing with it”* [CFM04]

*“I find some of them are not respectful to them. Some of them just talk down to them.” [CFM12]*

#### 4.6.2 Finding my way

Following diagnosis a number of participants within the CFM group and the person with dementia explained that they felt set adrift. This provoked an emotive response, as it was suggested that if the diagnosis was a chronic illness other than dementia, this might be different:

*“...but after 2 years both of them said right we’ve assessed you now you’re on the tablets there’s nothing more we can do. There’s no need for you to come back ... We felt as though we were abandoned and that we didn’t know where to go next ... If we were seen every so often, even to say well look nothing’s changed or it’s got a bit worse, or it’s got a bit better, at least you would feel that you were being looked after.” [COPWD1]*

*“Or you may go once, someplace that you can go every six months and they say “there’s nothing else we can do for you”” [AHPDO2]*

Finding information and/or one’s way through the available services was a pivotal concern, which could be linked to the perceived gap experienced by some following diagnosis, described in 4.6.2. Time was described as a precious commodity. Where procedural issues, system hold-ups or other difficulties were encountered, some CFM participants described contacting multiple information sources and sometimes giving up, as they did not have time to waste:

*“Yeah, I think, and information about where to go and what to do ... I rang, um, our local social welfare officer and, you know ... I didn’t ring back like” [CFM04]*  
*“got the form and I filled it in, got it filled in and we sent it away, and they said; “yes, you’re certainly entitled and it will come automatically next year”, but this year I got another form, ok, which I have to sign, and take and get witnessed, and you know, and half the time you say, “should I bother”” [CFM07]*

A number of CFMs described making the connections between services or deciding when it was time to return to or locate a new service rather than the other way around or working in partnership with professionals:

*“Oh we had to do everything on our own. No help! No assistance, there was absolutely nothing.”* [CFM01]

*“I had to find the next stage myself”* [CFM02]

*“...there was no other referral and nothing else happened... it’s a really big problem to find out anything, huge battle...”* [CFM05]

An informal network seemed to be an early port of call in terms of finding information. CFMs would speak to other CFMs, who they knew had dementia experience and would collect information in this way. Some of these participants described how they in turn now act as an information source to others:

*“I find that sometimes people ring me up here, people locally, because they know what has happened, you know, and they would ring me and ask for some help or advise, or you know, could I tell them where to go or what to do, you know, from times at the church, people would wait for me afterwards and talk to me about it ...”* [CFM02]

## **4.7 Making safe – constant vigilance**

This theme contains three categories and relates to the findings which describe the concept of protection in the study.

### *4.7.1 To tell or not to tell*

Diagnosis disclosure was an important consideration in terms of stigma and dementia. The issue of persons with dementia themselves indicating or disclosing a problem or diagnosis was referred to infrequently in this study. There were however frequent references to information disclosure by CFMs, i.e. if, when, how and to whom a

diagnosis of dementia is disclosed. Early in the illness, decisions around disclosure of dementia appear to be a particular issue and there was an overall feeling of reluctance to disclose the presence of dementia:

*“I didn’t want people to know, I just didn’t want the whole thing around us at all.”* [CFM02]

*“I do feel that there is a reticence in some people, and I’m not sure what it is about, because even when I explore with them, they kind of say they’ll think about it, maybe they are too polite to say to me, “well, no, I just can’t do this”, I think that’s an example of maybe feeling stigma, a sense of a stigma around dementia.”*

[AHPDO1]

The reasons for non-disclosure can vary. For some, not voluntarily telling others may be consistent with their characters, i.e. people who may not ever have had a close relationship with others beyond their immediate family. Non-disclosure here would consequently be an expected and normal practice:

*“Every case again is totally different, some people that would have been very secret of all their lives won’t want people to know, and you won’t change them”*

[AHPDO5]

Where the person with dementia has not been informed of the diagnosis, participants might decide not to tell others in case the person finds out. CFMs might also wish to prevent their loved one being seen in a different light by those around them. The vulnerability of persons with dementia was also cited as a reason for not wanting to disclose. Where a person’s diagnosis becomes known to others, this could potentially place the person at risk of being taken advantage of [AHPDO1]. For others, concern about what people would think of the person with dementia and by association the carer appear to be an issue. There were references to fears that transport coming to the house would display a logo which might publicise the presence of dementia [CFM10, AHPDO1, AHPDO4]. One CFM [CFM10] spoke of her initial unwillingness to tell neighbours due to

the shame she felt, while some participants spoke of how others knowing about the dementia might affect family standing in the community or social acceptability:

*“And another side to it is a lot of carers do not publicise it. Usually we would say to carers, “let your neighbours know”, because if they stray, but other carers say, “no, we have a good social life, if this gets out, we will be dropped like a hot cake”, and it has happened.”* [AHPDO2]

To some extent carers’ hands become forced as the illness progresses. For safety reasons it often becomes necessary to inform others. This was particularly so when there was a risk that a person with dementia may wander and become lost:

*“...eventually, a neighbour of mine ... she called me in one day, in the church into one of the rooms and she said to me; “look, you’re going to have to tell people, from the point of view that, people know, they look out for him, and they’ll bring him home if they meet him, they’ll walk along with him, without making a big thing of it, they’ll come home with him”.”* [CFM02]

AHPDOs also acknowledged the difficulties around telling or not telling. These participants spoke of their advice to CFMs and persons with dementia to tell close contacts early for safety reasons. A measured disclosure to those who could assist and/or provide support was suggested:

*“we would always advise people to let the neighbours know, for the simple reason that if they were in a bit of trouble or if the person wandered out of the house and the neighbours saw them they would be alerted ...”* [AHPDO4]

In contrast to those who spoke of a reluctance to tell others, there were examples of persons who had no difficulty with information disclosure and in some cases actively did so. Often these participants were those who reported that for them stigma related to dementia was not a particular concern.

#### 4.7.2 *Protecting the person with dementia*

Where discussed, the decision of whether or not the person with dementia was to be informed of the dementia diagnosis was related in part to a perceived need to protect due to the images, stereotypes and associations of dementia related stigma. For some however due to lateness of presentation informing the person with dementia may not be a consideration. The findings suggest that even early in the illness, the person with dementia may have a reduced awareness of their limitations. However the CFM seems to acquire a heightened and constant awareness of the person's needs and situation and a consequent need to protect:

*“The whole time, yeah, you're on alert all the time now...”* [CFM06]

Where this is the case the CFM may protect the person in terms of both safety and in interactions with others due to societal perceptions of dementia as a stigmatising condition. In the early stages, consistent with Goffman (1963) and Blum's (1991) research described in Chapter Two, some CFMs described engaging in a process of reminding the person with dementia and/or filtering, and amending his/her responses. This appeared to be designed to conceal or minimise the impact of the manifestations of dementia when in social interaction:

*“Absolutely and you see that happen all the time where you know a spouse will protect the person”* [AHPDO7]

*“he'd go to church, she'd sit at the back, ... she'd protect him, she'd put him on the inside so that nobody would speak to him or she would talk for him, she'd answer for him”* [CFM02]

As the illness progresses, again consistent with Blum's (1991) work, some participants described a process of 'getting there first'. Here the CFM pre-empted social discourse by discretely informing others that the person had dementia. Such actions were implemented with the intention of easing the way for the person with dementia and the CFM and forewarning or preparing those with whom the PWD and CFM come in contact:

*“I always go in first and I say; “Mum has is very forgetful”, now I say she has Alzheimer’s or I say she has memory difficulties but she doesn’t know... Because I just feel that, when because she doesn’t know she has a memory difficulty that when she meets them, that I don’t feel awkward or I don’t have to say, I say it before I meet them with Mum” [CFM04]*

There was also evidence that social contexts and spaces are chosen by the CFM to ensure their suitability for the needs and abilities of the person with dementia. It could be suggested that this is a form of protection from stigma, when the person with dementia manifests certain behaviours etc., which can result from a reduced ability to cope with environmental or social stressors. As described in 4.3.1, such behaviours may be perceived in a negative manner by others reinforcing the undesirable stereotypes and images associated with dementia:

*“...he went to certain restaurants so they knew, they got to know.” [AHPDO6]*

Actively chosen social isolation was a strategy adopted by some participants to protect the person with dementia and the CFM. (Of note this does contrast with efforts described by other participants to maintain social interaction.) Social isolation, which is an act of volition, appears to be a way in which to protect the person from the gaze of others, but differs from the enforced social isolation referred to in 4.5.2, as it is chosen by the CFM or person with dementia and not imposed against a person’s wishes:

*“I mean we used to go for a drink socially, right, and we had to stop doing that, because ... he now needed to be taken and showing where the toilet was ...Yes, but not because I cared about their reactions, but my pride was saying; “(NAME), how dare you look at my husband like that, who do you think you are?”, you know?” [CFM07]*

*“I think there is definitely from conversation that I’ve had with people, there’s definitely issues around a family member resisting the person, the individual actually being public, being participating in public because of the family member’s fear around stigma so...” [AHPDO10]*

Protection was also described by CFMs in terms of the need to monitor the quality of services received by persons with dementia. Some CFMs consequently adopt an advocacy role, to ensure that the person with dementia is treated in a fair and humane manner when his/her illness advances to the extent that the person may not be able to advocate on their own behalf:

*“Yeah, when somebody is in a general hospital, you have to be there, not saying that I didn’t want to be there, but you have to be there”* [CFM09]

#### 4.7.3 *Protecting close others*

There were frequent references by CFM and AHPDO participants to the protection of other close family members. This was frequently described in relation to the protection of children of people with dementia often by the person with dementia’s spouse or vice versa:

*“but even at that stage, my mother was trying to protect her family.”* [CFM01]

*“two of my (inaudible) girls went in apparently, I didn’t know this at the time but they went into the GP and they said; “don’t tell mummy that daddy has Alzheimer’s”... They were trying to protect me.”* [CFM02]

Protection of close others tended to be manifested in non-disclosure of a diagnosis or the extent of the implications of dementia for daily life. The reality of day to day living and the extent of coping or lack thereof may be hidden or minimised with the result that close others may not become aware until a crisis point is reached:

*“...even with their own children they will kind of try to camouflage the extent of the kind of symptoms and it’s somebody often when you know somebody like a spouse has to either take leave or is hospitalised [when] the family you know witness the sort of brunt of the kind of care giving role.”* [AHPDO7]

A number of participants, particularly CFMs, described having had more than one family member develop dementia prior to a spouse or parent. Where this is the case, it appears from the data that knowing what is ahead, as a result of previous experience, could provide an additional impetus to protect close others from the reality of dementia, including stigma related implications:

*“what happened was, my daughter’s father-in-law, had Alzheimer’s and had died, and you know, and I had an absolute horror of it, from hearing about it”* [CFM02]

#### **4.8 “Double whammy” – ageing and dementia**

References to societal and professional attitudes to ageing and the commonly held association of dementia with old age were frequent among the three groups interviewed. Participants described negative attitudes and apathy in relation to older persons:

*“It’s a valuing and a recognition of a person’s worth, you’re worth more when you are younger, they forget about the experience ... they have valuable contributions to make to society”* [AHPDO2]

There was a sense that dementia is sometimes perceived as an inevitable or expected accompaniment to ageing. Consequently, if a person develops dementia, he/she is doubly disadvantaged:

*“No there’s ageism and then there’s cognitivism, so I think they’re hit by kind of a dual stigma”* [AHPDO8]

*“Yeah it’s a double whammy isn’t it where they’re both victims of ageist attitudes by virtue of their growing old and then victims of you know negative attitudes by virtue of their having what might be considered a kind of mental health problem and a very stigmatising problem, so the two intersect resulting in their being very ostracised often- times by society”* [AHPDO7]

There was also a sense that people’s concerns might be subjugated or obscured in the presence of dementia. Some participants spoke of negative experiences with services and

the potential for dismissal of their health issues by health personnel, which they linked to prejudicial attitudes based on the combination of age and a dementia diagnosis. For example referral to non-dementia specialist services was highlighted by one participant as potentially problematic where a person was older and had dementia:

*“I find that when we go to see the GP ... that if we go with little problems, say aren't really taken all that seriously because we're, I suppose, we're old anyway because (name of person with dementia) has Alzheimer's” [COPWD1]*

#### **4.9 Viewing dementia as a disability**

A perception of dementia as a disability was suggested to be particularly desirable from the AHPDO perspective. The rights of those living with dementia were referred to, for example, the right to know, the right to be involved in decision making in terms of self and policy. The potential of viewing dementia as a disability in terms of addressing dementia associated stigma was referred to:

*“I suppose I feel so strongly about dementia as a chronic condition that people live with, it's a disability ... I want other people to realise this is not, why should it be stigmatising, you've done nothing to cause this, you know, change in your brain, anymore than the person who has, you know, cancer, has caused this condition, so why should you feel stigmatised by it?” [AHPDO1]*

*“I don't think we have really you know committed ourselves to considering it as a disability and then you know exploring all the different ways as a disability the illness can be supported.”[AHPDO7]*

This finding concurs with contemporary literature advancing dementia in terms of the tenets of the social disability model and its potential to contribute to the creation of supportive environments and attitude change. However, a participant working within the disability sector stated that there is:

*“... a risk when one uses ...the term stigma that one ends up talking about a condition of the person and I think that the experience with people with*

*disabilities has been that that has not been very helpful for them to progress in terms of better participation in society and it has been more to their benefit to focus on the prejudice and discrimination ...” [AHPDO10]*

One participant [AHPDO7] linked viewing dementia as a disability with a potential to support the maximisation of retained abilities and the promotion of quality of life in contrast to perceiving the person with dementia in terms of dementia related losses, which might mitigate against community involvement. The importance of enabling social participation for persons with dementia, the positive impact of contact with the community and the pursuit of life-long interests where feasible was referred to by participants from all groups. It was suggested that perceiving dementia as a disability could encourage the perception of the person with dementia in a holistic manner and emphasise social participation, inclusion and enhanced quality of life. However one AHPDO participant highlighted the need to be realistic and to consider both abilities and disabilities, due to the nature and progression of dementia:

*“It’s not either or, it’s ability and disability and unfortunately you get the kind of civil rights disability lobby who sometimes forget well actually you’ve got to look at the downside too! So it’s a mixture of combining the upside and the downside.”*  
[AHPDO8]

#### **4.10 The future – dementia ready**

Participants were asked to make recommendations to address the components of stigma. Many of the suggestions proposed were consistent with those identified in the wider stigma related literature and were targeted at personal, organisational and societal levels. As a preface to any specific intervention, one participant stressed the importance of any changes having enhanced quality of life as their primary aim:

*“I think that the most important thing we’re looking for at the moment, both of us is quality of life. That’s the only thing we can look for at this stage and I think that’s, that is so important. I think all stops should be pulled out to give us that.”*  
[COPWD1]

The need to facilitate attitude change was identified by some participants:

*“...I think that a focus on prejudice, discrimination and shifting attitudes by showing that the issue is not in the person but it’s in the environment. It’s in society ...”* [AHPDO10]

However, changing attitudes is known to be a difficult and slow process and requires intervention on a number of levels. Education to increase societal understanding was spoken about by a number of participants:

*“I still think there’s a huge lack of education for people who don’t have first hand experience of it. That needs to be maybe addressed or dealt with or just the fear taken out of it.”* [CFM05]

Education which is multi-faceted, age-targeted and intergenerational was advocated, as was the need for dementia specific education and experience for health professionals:

*“you know promote a more holistic and bio-psychosocial model of dementia care and seeing dementia more as a disability. And I think that that would help in the whole process of trying to advocate for people and trying to de-stigmatise.”* [AHPDO7]

One AHPDO participant particularly highlighted the need for dementia specific education for a range of professionals:

*“And I suppose you know education of all professionals, architects, engineers, lawyers, etc....”* [AHPDO7]

Measures to increase contact and community interaction for people with dementia were mentioned, including the need to consider environmental design and location of residential care, as was a need for involvement of people with dementia in self-advocacy:

*“People themselves I mean I guess you know, the more people who have a dementia are prepared to go public and talk about the experience.”* [AHPDO7]

*“...drawing on evidence from this disability perspective that self-advocacy in itself is empowering for a person ... where they're not seen as someone who is unable but is someone who is able to advocate on their own behalf ... So you know inclusive consultation and participation and people with dementia in developing programmes around tackling stigma, tackling prejudice that I think that would be very, very important.” [AHPDO10]*

In terms of addressing service difficulties which might be linked to potential structural discrimination, a number of suggestions were made:

The need to prioritise dementia as a policy issue and increase funding for resources was highlighted:

*“You see clearly until there's a broader policy support for people with dementia it's very hard for individuals to deal with these issues.” [AHPDO10]*

A seamless service where there is communication between the different health and social care system components was proposed to address variability and fragmentation of services:

*“... the other thing I do find difficult is that they don't all connect. The GP's doing his thing, the cardiologist is doing their thing, the Alzheimer's Society's here and they don't actually know what each other's doing and they don't connect.” [CFM05]*

Some participants spoke about the need for a designated person, potentially community based [AHPDO1], to facilitate information provision and individual guidance specific to the unique needs of each PWD and the CFM throughout all stages of the illness. A particular deficit in existing services was identified following receipt of diagnosis and before the need for intensive dementia specific services:

*“.. a different kind of support, like that just, you know, a kind of a one on one thing, and just, you know looking for kind of more information and, just where to go with it all to be honest, I think that's the thing.” [CFM04]*

In relation to the availability of person-centred dementia specific services, as dementia advances, increasing such services would be desirable and could increase carer support and activity and social participation for the PWD:

*“I see both kind of carers walk in the door, but I think, you know, really the need for support is enormous, the need for more funding, the need for day-care centres, the need for specialist environments, you know.”* [AHPDO1]

*“I believe we need a specialism which ... has a dementia focus, and in a way that’s when we crack, the whole stigma thing.”* [AHPDO1].

Finally service flexibility in terms of the type and timing of services was identified as crucial, for example out of hours, twilight and weekend services, continuity in care routines from one care context to another and age-specific services which meet the needs of younger persons with dementia:

*“... so I think there is a huge issue around flexibility and the preparedness of the system to work with and maximise vital potential of people with dementia”*  
[AHPDO8]

#### **4.11 Summary**

This chapter presented the research findings using the thematic structure which emerged following the process of data analysis. Due to the exploratory nature of the research, the findings are limited to the current study, however a number of issues have emerged, which require consideration and these along with the study recommendations will be addressed in the following chapter.

# Chapter Five - Discussion and Recommendations

## 5.1 Introduction

The purpose of this research was to conduct an exploratory study of dementia related stigma, and the impact on all those affected. Rather than existing as a discrete entity, an important finding was that experiences of dementia related stigma, for many participants appeared to be embedded in the overall experience of dementia. This was particularly apparent for the person with dementia and carer/family member participants. Stigma emerged as a concept of relevance more to the professionals interviewed; for carers and the person with dementia it was the issues that made up the components of stigma (including; social unacceptability, social isolation, policy and services disconnects, structural discrimination, and devaluation), rather than the word itself, that were of more relevance to their lives and experiences. A number of important points for discussion emerged from the research findings and are considered with reference to the available literature. A series of recommendations emerging from the study and implications for future research will also be presented.

## 5.2 Discussion

### 5.2.1 *A Contrasting View of Stigma*

For a few of the participants the word stigma was not directly associated with dementia. Most participants however spoke directly about stigma or its components. Most classical analyses of stigmatisation assume the person who receives a diagnosis is subject to stigmatisation, or is a helpless victim who internalises devaluation, labelling, discrimination etc and acquires a damaged personality (Crocker, 1999; Dinos et al., 2004). In contrast, some writers suggest that stigma is a matter of degree, in which persons can become active challengers (Reisman, 2000; Link and Phelan, 2001). There were participants who expressed both of these views. In several other studies participants highlighted positive outcomes of their illness and/or felt that attitudes could be changing

for the better (Morgan et al., 2002; Myrra et al., 2005). Such improvements in public awareness and understanding were reported by some participants in this study, “*I think society is much more aware of it, you know*” [CFM02]. However, for most participants improved awareness and understanding was not their experienced reality. As one participant put it, “... *it’s the stereotypical kind of views that I think still exist really and ... the misconceptions you know just overall kind of ignorance...*” [AHPDO7].

There were variations and differences in the views expressed by the three groups of participants. Overall findings were consistent with previous reports. Many of the allied health professional and disability organisation participants tended to speak in professional terms and use formal language to refer to stigma and dementia related issues. These participants were more likely to speak in terms of the broader picture for people with dementia, “...*I think the inclusivity of people with disabilities is less than a hundred per cent and it’s worse for people with a cognitive memory loss*” [AHPDO8]. This contrasts with the person with dementia and the carer/family member group, who generally spoke from a personal perspective, “*I do often find my father sitting in the room, just pushed in ... just looking at a wall*” [CFM01]. Allied health professional and disability organisation participants with personal experience of dementia often tended to speak from both the global and their personal experiences. These differences in personal and professional perspectives are likely to have impact upon relationships between carers and persons with dementia and services providers seeking to assist them; an area that merits further study.

### *5.2.2 Experiencing stigma and its components*

Several components of stigma emerged as critical concerns and experiences of the participants: social unacceptability, social isolation, policy and service disconnects, structural discrimination, and devaluation.

*Social Unacceptability.* There was frequent comment on the social unacceptability of dementia. Participants spoke of images and stereotypes of people with dementia, such as people with dementia are violent, “*I have noticed an increasing tendency to associate*

*dementia with disturbed behaviour or violent behaviour and I think that that is very worrying trend in terms of society's response to dementia*" [AHPDO10]. Instances of social isolation and avoidance by friends, colleagues and the public were spoken about. The interviews confirmed that a diagnosis of dementia is clearly not simply a medical process, it is also a social act that places the person with the diagnosis in a new social group (Cayton, 1993). Social distance from those who are stigmatised has received a lot of attention. Goffman (1963) and Albrecht, Walker and Levy (1982) report that social disruption in interactions between those subject to stigma and those with whom they come into contact, can result in either rejection or withdrawal by either side. Participants presented their experiences in similar terms, *"I think, it's very isolating disease really, and, I feel people don't come to visit,"* [CFM02], *"In terms of socially, I think people withdraw from social situations because of, quite often because of embarrassment because they might forget things or they mayn't be able to hold a conversation the way, so there would be a withdrawal from social outings and there would also be withdrawal from hobbies"* [AHPDO3].

*Social Isolation.* Social isolation can have a significant impact on those affected by dementia and may reinforce dementia related stigma. Participant statements here were consistent with previous reports that voluntary withdrawal by those with dementia and/or their carers may be chosen to protect the person from the gaze of the outside world or as a means to ensure that the person with dementia does not find him/herself in a context unsuitable to their needs. There were also findings that support a role for the carer/family member in Blum's (1991: 264) words, as a 'team leader' mediating potentially discrediting dementia related information, particularly as dementia advances. Findings here support a view of the carer needing to be constantly vigilant, which was evident in terms of meeting direct care needs, protection of the person with dementia, ensuring the quality and delivery of services, and encouraging continued respect for the personhood of the person with dementia. *"Well, really now, we go, we spend a lot of time with family, our own family and actually my husband's family, and they are great with her, you know, and they include her in everything"* [CFM04]. However, the constant and protracted nature of this role was reported to take its toll on the primary carer, *"I was working nights and I*

*was working, like I was in at two o'clock during the day so, and working right through maybe sometimes until two in the morning, really long hours, and, you know, I was just becoming more and more stressed, and worn down, and worried...*" [CFM04].

*Policy and Services Disconnect.* Disconnections in policy and services have previously been noted in an Irish context for disability and ageing populations. D'Eath et al. (2005) referred to service fragmentation and its impact on the quality of service provision for people with disability and Lane et al. (2000), in relation to the needs and experiences of carers of older people, reported bureaucratic constraints, in terms of service access and lack of recognition of carers needs by service providers. That dementia related stigma and its components exist in society, creates a similar likelihood that they may permeate institutional policy and have a pervasive impact on service users' experiences. While instances of exemplary experiences with health and social care services and personnel were noted in the current study, the opposite was also found. Examples cited included: bureaucratic difficulties such as difficulties accessing entitlements, delays in or reluctance to diagnose dementia particularly by some GPs, delays in referral and service provision, and inadequate or insufficient services, including twilight care, weekend and out of hours care. One participant gave the example of needing care assistance between 7.30am and 9am to enable her to get ready for work, but such assistance was not available before 9am. Lack of resources does not appear to be a sufficient explanation for these kinds of disconnects and barriers to successful care. They may also speak to the value being placed on both the person with dementia and the carer.

Service fragmentation was also referred to and several carers/family members spoke about how they had to act as the communication link between the different services they were attempting to access. In particular participants noted their frustration at the lack of supports, including information, after they received the diagnosis. For some, services only became available when there were substantial care support needs, "*We had to fight then to get him respite so we could sit around my mother's bed while she was dying, and that, you know, and we could speak out and we could put the fight up but other people may not be able to, because we were able to do that, and we got the respite for two weeks*

*but we were warned when we went in that this is two weeks and two weeks only,”* [CFM01]. Frustration and anger relating to service disconnect and fragmentation experiences, appeared to contribute significantly to the overall emotional consequences of dementia. Carer difficulties and isolation were further compounded by the guilt they felt was imposed by societal expectations in relation to caring, *“And I also feel that, people talk about guilt, as regards, I mean to finally go to full time care, that the carers would feel guilt about that, I don’t think that’s right, and I don’t think that, guilt should ever be mentioned to carers, if they’ve done their best, they’ve done their best.”* [CFM02].

*Structural Discrimination.* The service related concerns found in this report speak to the issue that people who are subject to stigmatisation are potentially at risk of structural discrimination (Link and Phelan, 2001). This contradicts the prioritisation of people centredness, enhanced service integration and implementation specified in the Action Plan for Dementia (O’Shea and O’Reilly, 1999), and by Quality and Fairness A Health System for You (Department of Health and Children, 2004). In this study, participants reported feeling that structural discrimination was not discrimination by intent, but was the result of a failure to prioritise and adequately resource dementia services. *“I think that there’s definitely insufficient services I don’t think it’s a deliberate policy of social exclusion I think it’s such a rapidly changing area that there has been no provisions up until not that long ago we didn’t really need to bother but now with you know population trends as they are and with longevity there’s an urgent need to do something fairly, you know fairly rapidly. And I guess it’s a costly illness too ...”* [AHPDO7]. The challenge for service providers and policy makers is to consider to what extent lack of planning is due to lack of foresight regarding population trends, or to not valuing a particular group (people with dementia and their carers) or valuing the needs of other groups more. Honest answers to this consideration will help establish the extent to which stigma impairs service provision for this population. At the very least it should encourage a re-examination of the value placed on individuals.

*Devaluation.* References were made to devaluation of the person with dementia, such as neighbours speaking over the person and the loss of previous ways of being, including

having to cease employment and changes in family roles. Some participants referred to experiences of devaluation, described in terms of the way people with dementia were spoken to or treated by professionals and of the devaluing of carers/family members' experiential knowledge, "*he was getting no assistance ... the impression I got from this major hospital was "so what, he's only a patient out of a nursing home his mind is not right"*" [CFM01]. The potential for professionals to augment the attribution of stigma via their behaviours and interactions with service users has been identified in previous research (Wahl, 1999; Angermeyer, Schulze and Dietrich, 2003). A tendency to stereotype older people with dementia was noted by a number of participants. It was suggested that older people are subject to both ageism and dementia related stigma. This is consistent with previous reports, of age discrimination in service access and availability, difficulties in getting referrals to specialist services and service fragmentation in Irish health and social services (McGlone & Fitzgerald 2005). The compounding effect of these levels of stigmatisation have previously been highlighted by McColgan (2004), while Quin and Redmond (2003: 8) use terms such as 'double jeopardy' and 'simultaneous disadvantage'.

### *5.2.3 Challenging stigma in dementia – a social disability approach*

It has been suggested that a social model of disability can provide a framework to better understand dementia, including the potential to challenge assumptions (Gilliard et al., 2005). A social model of dementia has a focus on how people experience dementia in their lives (Bond, 2001) and emphasises the contribution of others and of social institutions to the disability that people with dementia experience including the economic, political, cultural and environmental barriers they encounter (Barnes, 2003; Cantley and Bowes, 2004). In this view it is not impairment that is the main cause of people's problems but the way society responds to people as an oppressed minority (Oliver, 2004). The nature of dementia does differentiate it from many other disabilities. Consequently the goal may be less about normalisation for the person with dementia, and instead should be focused upon finding ways in which the retained abilities of the person with dementia can be enabled and, on a broader level toleration and acceptance of difference

encouraged, *“I think we have to work with the retained ability and think how can we make these years, ‘cos lets face it dementia can go on for many years, how can we kind of make things more pleasant for the individual and you know provide some meaning to the person’s life when you know they’re experiencing so many multiple losses”* [AHPDO7]. Within the literature there is some debate surrounding the use of the social disability model for dementia (see Gilliard et al., 2005). When considering dementia as a disability, there is a subsequent need to understand its chronic and progressive nature and the implications of this in terms of other forms of disability and policy.

A disability perspective encourages the belief that individual level interventions need to be accompanied by measures that deal with deeper and more institutional and societal causes of and supports for stigma (Parker and Aggleton, 2003). Moving the focus of attention from the experience of stigma for the individual with dementia to questioning and challenging societal responses to those with dementia alters our conceptualisation of stigma to social exclusion (Rogers and Pilgrim, 2005). A number of the participants, particularly those in the allied health professional and disability group did refer to dementia as a disability or suggested the need to re-conceptualise dementia as a disability, *“I feel so strongly about dementia as a chronic condition that people live with, it’s a disability”* [AHPDO1], *“Well I think that there could be a lot of application of the social model of disability and dementia...”* [AHPDO10]. Other participants may not have viewed dementia in this manner, perhaps because dementia as a disability may not yet have achieved recognition among the public. This finding of a more narrow view of disability is consistent with other Irish research which found that 80% of general public respondents saw disability in terms of physical disability (National Disability Authority, 2002). Yet there are many parallels in dementia and disability. The influence of social factors and social definitions on the experience of disability is widely accepted (National Disability Authority and The National Council on Ageing and Older People, 2006). The experience of dementia has a similar range of impacts on the social world of the person with dementia and their carers/family members.

#### 5.2.4 *Moving forward – from social exclusion towards social inclusion*

Ultimately endpoints of stigmatisation are social exclusion and discrimination (Last, 2000). Burden and Hamm (2000) suggest that social exclusion exists where levels of material well-being, social benefits and positive estimation of social status and identity are insufficient. Social exclusion then impacts on self-identity in people with dementia and can predispose the person to stigma and loss of dignity. In the current study, some carers/family members described similar experiences, including the withdrawal of friends and their difficulty in maintaining social and occupational roles. These reports are consistent with the literature relating to stigma by association or courtesy stigma. Social exclusion leads to disempowerment and potential marginalisation and may in dementia inhibit control, participation in decision making and lead to infringement of the person with dementia's rights as a citizen (Cantley and Bowes, 2004). Such sentiments were echoed by some participants: “ ... *the inclusivity of people with disabilities is less than a hundred per cent and it's worse for people with a cognitive memory loss*” [AHPDO8].

It has been stated that despite acknowledged service developments, people with disabilities in Ireland remain subject to marginalisation (Quin and Redmond, 2003). This also appears true for people with dementia. In order to address social exclusion concerns for people with dementia and their carers/family members, ways need to be found to facilitate their social inclusion, i.e., to support opportunities and resources necessary for greater participation in economic, social and cultural life (Delaney, Cullen and Duff, 2005). This will require clarification of the meaning and interpretation of social inclusion for people with dementia, a point echoed by Cantley and Bowes (2004). Social inclusion has been identified as an important objective in terms of social partnership. According to the Sustaining Progress: Social Partnership Agreement (Department of the Taoiseach, 2003: 64), “the core objective is to build a fair and inclusive society and to ensure that people have the resources and opportunities to live life with dignity and have access to the quality public services that underpin life chances and experiences”.

Knauss and Moyer (2006), dementia advocates in the United States, argue that only those who are living with dementia can know what it is like and that those involved in policy

making, service delivery and research consequently need to hear from those living with dementia until such persons “cease to be a sideshow and instead are full participants in the work” (69). This report is an effort to explore and give voice to the person with dementia and his/her carers in relation to what the experience of dementia and specifically dementia related stigma is like for those affected. Many of the participants here appeared more focused upon the components of stigma that influence their daily lives than on stigma itself. The findings of this study therefore suggest that it will be in the addressing of the components of stigma, and the development of person-centred responsive services that greater inclusion will be facilitated: “...on the way a society can accommodate, you know create better accommodations for someone, facilitate them, support them ...” [AHPDO10].

### **5.3 Study limitations**

- Due to the nature of the research and the time-frame available, the production of a formal theory of stigma in dementia was not intended. The findings of this study have illuminated an area about which there is limited knowledge and they provide preliminary data both to guide initial change efforts and to support further research.
- Twenty-three interviews were conducted with a range of participants who facilitated an exploration of the expression of dementia related stigma from multiple perspectives. While efforts were made to recruit people with dementia, only one person with dementia was interviewed. The difficulties of recruiting people with dementia to participate in research are acknowledged. Identifying ways to include the perspectives of more people with dementia would be desirable in future related research.
- The data were derived from interviews conducted in a limited number of geographic regions in Ireland. Despite this, participants representing multiple formal and informal caring contexts were successfully interviewed.
- The study findings represent participants’ accounts only, in contrast to observation of the issues recounted. From a pragmatic point of view, observation

would have been difficult and inconsistent with the exploratory nature of the study, as it was the participants' perceptions and experiences of dementia related stigma that were sought.

#### **5.4 Conclusion**

Although the research brief was to investigate issues of stigma in dementia, no assumptions or pre-determined framework or lens was imposed on the data collection or analysis. The data was allowed to speak for itself. The findings of this study clearly indicate that people with dementia and their carers are often subject to attitudes and experiences, which encourage isolation from usual support networks, social distance from others in society, difficulties in navigating the available systems and services, and threats to self-esteem and personhood. These are experiences associated with belonging to a stigmatised group. Most participants either referred to stigma and/or its components, but some did not directly associate their experiences with the word 'stigma'. For many people interviewed in this study, particularly family carers, meeting care needs and finding services and information were more pressing. Yet when such carers spoke of the difficulties they encountered, components of stigma such as discrimination, devaluation and stereotyping were clearly apparent. Consequently, rather than focusing on stigma alone, efforts to address dementia related stigma need to respond to the issues which the participants identified as problematic including; social isolation, fragmented, unsuitable and poorly resourced services, lack of information and difficulty in navigating a complex health and social care system, in which services are often unresponsive to the real needs of people with dementia and their carers.

A central finding in this study was that the daily concerns and day to day toll of care-giving was burdensome in its own right, and was confounded by the additional burden of social isolation and poorly developed and fragmented services. Why this disconnect between needs and services? A key challenge for service providers and policy makers is to understand to what extent the service difficulties are due to lack of planning in terms of the implications of a growing ageing population or due to either not valuing a particular

group (people with dementia and their carers) or valuing the needs of other groups more. Honest answers to such considerations will help establish the extent to which stigma impairs service provision for this population. At the very least it should encourage a re-examination of the value placed on people with dementia and their carers. The findings support a view that dementia is a complex and multi-faceted disability and dementia related stigma, where experienced, is embedded in the overall experience and can have extensive effects on the lives of people with dementia and by association their carers/family members. For change to occur, i.e. for stigma to be reduced and social inclusion increased, this complexity must be recognised and society in general and services providers in particular must own their role in its assignment and maintenance and become active agents for change. Successful intervention to address stigma will be equally complex and multi-levelled and must target the components of dementia related stigma identified here, including: social unacceptability, social isolation, policy and services disconnects, structural discrimination and devaluation.

## **5.5 Recommendations**

### *5.5.1 Recommendations for policy*

- In terms of policy, dementia must be treated as a high priority policy issue. While An Action Plan for Dementia (O'Shea and O'Reilly, 1999) was devised, its contents have yet to be fully implemented. More attention, more resources, and a real and lasting change in how dementia is conceptualised and approached by our society are all still needed.
- Specific health and social care policies are needed or must be revised to counter dementia related stigma.
- Greater levels of resources are needed to augment the availability, accessibility and usefulness of person-centred dementia specific services that support the abilities of people with dementia.
- Current services must be reviewed and the system fragmentation and lack of communication reported by participants addressed, with the intention to create a seamless system.

- New ways are needed to ensure that the citizenship and social inclusion of people with dementia and their carers/family members are respected and ensured.
- People with dementia must be involved with policy planning and development.
- There is a need to further develop a robust advocacy movement to lobby for and with people with dementia and carers/family members.

The Alzheimer Society of Ireland, National Council on Ageing and Older Persons, The National Disability Authority and other interested agencies and organisations involved in planning and advocating for policy changes have important roles in ensuring that these issues are raised and addressed in appropriate policy arenas. However, more immediate change in the way services are delivered is possible; the Department of Health and Children and the Health Services Executive and other relevant state agencies may rely on the mandates of existing policy documents, such as An Action Plan for Dementia (O’Shea and O’Reilly, 1999), Sustaining Progress: Social Partnership Agreement. 2003-2005 (Department of the Taoiseach, 2003), Quality and Fairness; A Health System for You (Department of Health and Children, 2004) and Towards Best Practice in Provision of Health Services for People with Disabilities in Ireland (Pillinger, 2004).

### *5.5.2 Recommendations for service planning*

- A priority should be the establishment of a core of community based case managers, involved from the time of diagnosis throughout the dementia continuum, as a resource for people with dementia and/or their carers/family members.
- A package of flexible person-centred services which can change to suit the needs of an individual as a dementia progresses including; services designed to meet the needs of younger people with dementia, services that can be offered at diagnosis and through each stage of dementia, and services that meet out of hours, weekend and twilight needs.
- The involvement of people with dementia and/or their carers/family members when devising personal care plans, to ensure that service provision meets their identified needs and wants.

These recommendations respond to the direct daily challenges for people with dementia and their carers/family members. Some policy changes may be needed to support their implementation, but it is likely that solutions already lie within the remit of Department of Health and Children and the Health Services Executive and with physicians and other health and social care professionals, changing care practices to ensure inclusivity of people with dementia and their carers/family members and to recognise and uphold the continuing abilities of people with dementia. Advocacy by people with dementia themselves, carers/family members, the Alzheimer Society of Ireland, National Council on Ageing and Older Persons, The National Disability Authority and others will also be required, to ensure that concrete steps are taken to implement such recommendations.

### *5.5.3 Recommendations for information provision and education*

- Dementia specific education is recommended for health, social care, legal and environmental planning professionals.
- Education programmes must convince recipients of the importance of stigma, challenge stereotypes and offer strategies to address the components of stigma including prejudice and discrimination.
- Existing media awareness campaigns should be continued, collaboration with the media should be expanded and specific efforts undertaken to illuminate and challenge the components of stigma in dementia.

Media outlets and educational institutions are already doing a lot in respect to these recommendations and their contributions are acknowledged, as is the fact that they have other pressing public information and training priorities to address. However, this study clearly illustrates that people with dementia and their carers need more information and better informed providers. Each professional area working with people with dementia and each institution in Ireland preparing such professionals, must commit to addressing stigma and challenging stereotypes. Changing the views of society and professionals about dementia will further require the sustained support of the Alzheimer Society of Ireland, the media, the Dementia Services Information and Development Centre the

National Council on Ageing and Older Persons, The National Disability Authority, and other interested organisations.

## **5.6 Implications for further research: setting the research agenda**

- The impact of stigma or its components on dementia policy and on the practice of professional care requires further exploration, particularly the influence of discrimination, prejudice and stereotyping.
- There is scope to create a theory which outlines how the components of dementia related stigma impact on the relationship between those affected by dementia and health and social care professionals. Such theory development may then help guide the development of education and intervention programs designed to address and contain stigma related concerns.
- Where service providers have personal experience of dementia, there is the potential to explore the effect on professional perspectives and how this might impact on relationships between service providers and carers and people with dementia.
- Research is needed to support the design, implementation and evaluation of regional integrated approaches to services and on how policy, training and media approaches may impact upon dementia related stigma, including changes in dementia knowledge, attitudes and behaviours.
- Research that investigates the nature of relationships between those with dementia and those around them, family, neighbours, the local community, may help illuminate how stigma and its components affect social interaction and constructs such as social distance.

The research funding priorities of the Health Research Board, the National Disability Authority, the National Council on Ageing and Older persons and of other public and private funders, should include the addressing of stigma related issues and the development of more responsive evidence based service approaches. Existing research groups should also develop the needed research designs and expertise to support these priorities.

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# Appendices

## Appendix 1 - Six dimensions of stigma

1. *Concealability* – Is the condition hidden or obvious? To what extent is its visibility controllable?
2. *Course* – What pattern of change over time is usually shown by the condition? What is its ultimate outcome?
3. *Disruptiveness* – Does it block or hamper interaction and communication?
4. *Aesthetic qualities* – To what extent does the mark make the possessor repellent, ugly or upsetting?
5. *Origin* – Under what circumstances did the condition originate? Was anyone responsible for it and what was he or she trying to do?
6. *Peril* – What kind of danger is posed by the mark and how imminent and serious is it?

(Jones et al., 1994: 24).

## Appendix 2 - Gant Chart Illustrating the Research Timeline

	March 2006	April 2006	May 2006	June 2006	July 2006	August 2006	September 2006
Research team appointed	→						
Gaining ethical approval	→	→	→				
Literature review		→	→	→	→	→	
Field work			→	→	→		
Transcription			→	→	→		
Data analysis			→	→	→		
Draft report						→	
Final report							→
Report launch							September 21 <sup>st</sup> 2006

### **Appendix 3 – Inclusion criteria for potential participants**

You are invited to participate in this study if you fulfill one of the following sets of criteria:

**Person with dementia:**

- You have dementia
- You are willing to voluntarily participate in the study
- You understand the purpose and process of the research

**Note:** You are welcome to have a carer/family member present during the interview.

**If you are a Carer/family member:**

- You are caring for or have cared for a person with dementia
- You are willing to voluntarily participate in the study
- You understand the purpose and process of the research

**If you are an allied health professional or working in the area of dementia care:**

- You are an allied health professional with experience of caring for persons with dementia Or
- You represent a disability organisation or other agency with knowledge and/or experience of stigma and/or dementia
- You are willing to voluntarily participate in the study
- You understand the purpose and process of the research

## Appendix 4 - Background information people with dementia

Participant code: \_\_\_\_\_

Participant's Age: \_\_\_\_\_

Male  Female

Occupation/Previous Occupation: \_\_\_\_\_

Where does the person live?

Urban location  Rural location  Living alone   
Not living alone

If not living alone, who is the person living with? \_\_\_\_\_

Is the person: Single  Married  Widowed  Widower

Other \_\_\_\_\_

Children: Yes  No

Who is the primary carer (e.g. spouse) \_\_\_\_\_

Is the primary carer living with the person with dementia:

Yes  No

Length of time since diagnosis: \_\_\_\_\_

Type of dementia (if known)? \_\_\_\_\_

Services Accessed \_\_\_\_\_

## Appendix 5 - Background information carers/family members

Participant code: \_\_\_\_\_

Relationship to the person with dementia: \_\_\_\_\_

Person with dementia:     Alive                    Deceased

Carer/family members's age: \_\_\_\_\_

Male                Female           

Where does the carer/family member live?     Urban      Rural

Is the carer/family member living with the person with dementia?

Yes                    No                    N/A

Is the person:           Single      Married      Widow      Widower

Other \_\_\_\_\_

Children:     Yes      No      If yes, how many? \_\_\_\_\_

Length of time since relative/family member's diagnosis: \_\_\_\_\_

Type of dementia (if known): \_\_\_\_\_

Total number of years caring (to include time since admission to continuing care if applicable): \_\_\_\_\_

Number of years full-time caring: \_\_\_\_\_

Number of years part-time caring (excluding time since admission to continuing care if applicable): \_\_\_\_\_

Is the carer working outside the home?     Yes      No

Occupation: \_\_\_\_\_

Services Accessed: \_\_\_\_\_

**Appendix 6 - Background information – allied health professionals and disability organisation participants**

**Participant code:**

**Discipline (if appropriate)** \_\_\_\_\_

**Job Title** \_\_\_\_\_

**Type of organisation that participant represents (if appropriate):**

\_\_\_\_\_

**Number of years working in dementia care (if appropriate):** \_\_\_\_\_

## **Appendix 7 - Exploring stigma in dementia: interview guide for people with dementia and carers/family members**

### **Topic guide:**

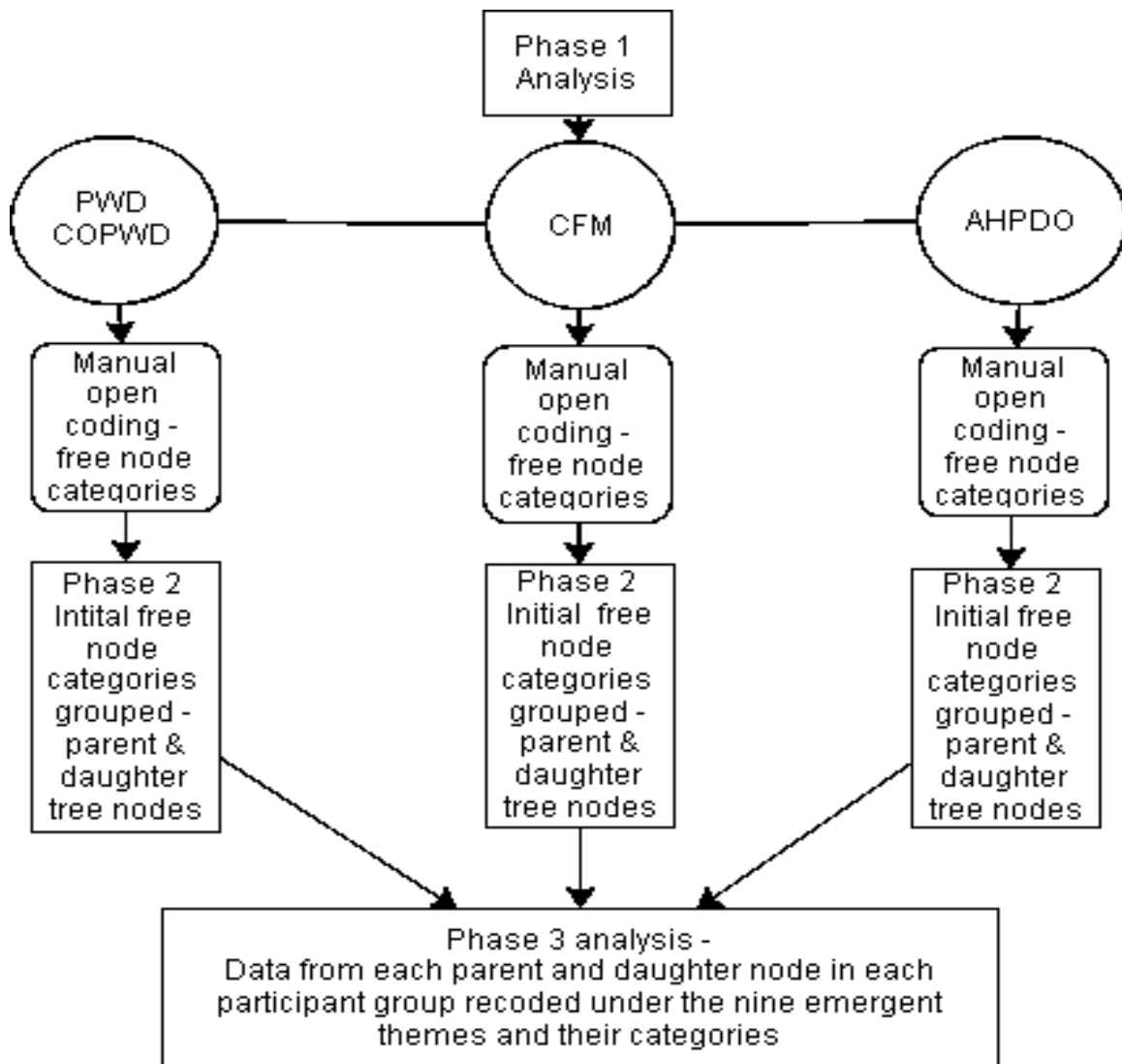
- Route to diagnosis
- The dementia experience
- Adjustment
- Effect on relationships
- Social outlets / social support (before dementia & current)
- Quality of life
- Feelings
- Disclosure of the dementia diagnosis
- How you feel society & close personal contacts perceive/treat you/your family
- Coping mechanisms/strategies
- Relationships with/access to your general practitioner, other health and /or social care professionals
- Media representations
- The future
- Do you feel stigma is/was an issue for you? OR Have you ever experienced stigma?

## **Appendix 8 - Exploring stigma in dementia: interview guide for allied health professional and disability organisation participants**

### **Topic guide:**

- Diagnosis, and its impact/implications
- Diagnosis disclosure
- The dementia experience – adjustment, approaches, management, difficult aspects
- Relationships with persons with dementia, their carers/family members
- Access to health and social care services
- How society perceives persons with dementia
- Perceptions/experience of stigma and dementia
- Carers/family members and stigma
- Perceptions/experience of discrimination and dementia
- Strategies to address perceived stigma
- The future

**Appendix 9 – Model illustrating the process of analysis which led to the thematic structure of the findings**



Please note the following abbreviations are used:

PWD = Person with dementia

COPWD = Carer of the person with dementia interviewed in the study

CFM = Carers/family members

AHPDO = Allied health professional/disability organisation participant